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The use of the results from economic evaluation in applied decision-making in the UK health service

THE USE OF THE RESULTS FROM ECONOMIC EVALUATION IN APPLIED DECISION-MAKING IN THE UK HEALTH SERVICE

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Abstract

There is a strong role for local health care organisations to manage and deliver care for their local population. Within this context, rationing is inevitable, since there will never be enough resources to cater for all needs. Economic evaluation is proposed as one way to achieve explicit rationing, acting as a useful aid to decision-making. The Government promotes use of economic evaluation and millions of pounds are spent on the production of economic evaluations each year. How, and whether, economic evaluation actually aids local decision-making in practice is a relatively under-researched area and further research is required.

In this study, qualitative methods were employed to explore the views and perceptions of decision makers. 29 interviews were conducted with health care commissioners and providers, and 12 priority setting meetings for cancer care were observed. 15 interviews were also conducted with health economists.

Findings suggest that economic evaluation is not used. It appears that there is an informal process of decision-making in which use of evidence is marginalised. Further, economic evaluations are rarely relevant to the type of decisions made locally, which tend to concern implementing national decisions and making 'management decisions' about the employment of extra staff and new equipment. The study also found that some health economists might also have the incentive to produce work that allows them to progress 'up the career ladder', rather than work that is useful to local decision makers.

Economic evaluation intended for local level population 'decision-making' may therefore have no clear audience. Economic evaluation should perhaps be reserved for situations where it will clearly influence *national* level decision-making. At the local level the more flexible tool of programme budgeting and marginal analysis may be better able to meet the requirements of local resource allocation.

To Mohammad and Ali

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Declaration

The author of this thesis carried out all parts of this research. This thesis is based on the original work of the author. Where published sources have been used, full reference has been made and all advice and assistance received has been acknowledged.

Any views expressed in this thesis are those of the author and do not necessarily represent the views of the University of Bristol. The author accepts responsibility for any errors remaining within the work.

This thesis has not been previously submitted for any other degree in this University or any other.

SIGNED: O.M. Asim DATE: 21-11-06

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List of abbreviations

Abbreviation	Expanded
A&E	Accident and Emergency
ACT	Assertive Community Treatment
AHB	Area Health Board
CBA	Cost Benefit Analysis
CEA	Cost Effectiveness Analysis
CEAC	Cost Effectiveness Acceptability Curve
CG	Cancer Group
CHD	Coronary Heart Disease
CHI	Commission for Health Improvement
CN	Cancer Network
CT	Computerised Topography
CUA	Cost Utility Analysis
DALY	Disability Adjusted Life Year
DCE	Discrete Choice Experiment
DoH	Department of Health
DTC	Drug and Therapeutic Committee
EBM	Evidence Based Medicine
EE	Economic Evaluation
EED	Economic Evaluation Database
EVPI	Expected Value of Perfect Information
EUROMET	European Network on Methodology and Application of Economic Evaluation Techniques
GP	General Practitioner
HA	Health Authority
HCC	Health Care Commission
HEART	Health Economists' Activities, Research and Teaching
HESG	Health Economists Study Group
HIMP	Health Improvement Modernisation Plan
HMO	Health Maintenance Organisation
HTA	Health Technology Assessment
ICER	Incremental Cost Effectiveness Ratio
IHEA	International Health Economics Association
LDP	Local Development Plan
LREC	Local Research Ethics Committee
MCO	Managed Care Organisation
MRI	Magnetic Resonance Imaging

MS	Multiple Sclerosis
NB	Net Benefit
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSB	Net Social Benefit
NSF	National Service Framework
PBAC	Pharmaceutical Benefits Advisory Committee
PBMA	Programme Budgeting and Marginal Analysis
PCT	Primary Care Trust
PET	Positron Emission Topography
PFI	Private Finance Initiative
SG	Service Group
SHA	Strategic Health Authority
TB	Tuberculosis
QALY	Quality Adjusted Life Year
QOL	Quality of Life

List of health economics terminology

Term	Explanation
Economic evaluation	Comparison of alternative options in terms of *costs and outputs*. Synonymous with pursuit of *efficiency*
Efficiency	The relationship between inputs and outputs. To be efficient means maximising outputs in relation to inputs. There are two types: *Technical efficiency:* addresses whether production of output occurs in the best way possible without wasting any resources *Allocative efficiency:* addresses whether production of the pattern of output best satisfies consumer demand (assuming that prices reflect consumer demand in perfect markets)
Opportunity cost	The value of foregone benefit which could be obtained from the next-best alternative use
Scarcity	All resources are limited in supply
The Margin	Economists are typically interested in marginal or incremental changes (for instance, what are the costs and benefits of expanding an oncology unit in a hospital?), because of the relationship with efficiency. So, for instance, the average benefit can increase from expanding a unit, but the marginal benefit of expanding the unit to the *n*th degree might not be worth the cost
Utility	Measure of satisfaction, well-being, or pleasure

Executive summary

Health economics is the discipline of economics applied to the health care system. Health economics rests on the fundamental economic principles as the rest of economics: scarcity of resources, opportunity cost, and the margin (defined in the list on the previous page). Health economics research typically examines areas such as: health system planning; demand for and supply of health care; determinants, and valuation, of health; and evaluation of diagnostic and therapeutic procedures. Economic evaluation can potentially advise decision makers on how to achieve the greatest health gains within available resources. Without an appropriate economic basis for decision-making, it could be that services and treatments that are not proven to be efficient are commonly delivered, whereas those that are proven efficient are not delivered. Economic evaluation is seen to be increasingly used in the health sector, particularly in the Western World (North America and Western Europe)[1] partly due to the evidence-based decision-making environment in these areas.[2]

There has been an increasing number of economic evaluations performed in health care over the past thirty years.[3] For instance, there were approximately one hundred evaluations of tuberculosis (TB) control between the years 1982 and 2002, compared to the relatively small amount of work in previous years.[1] However, little is known about the influence of economic evaluation on health care decision-making,[4, 5, 6, 7] although there is a growing concern that it is, in practice, limited.[7, 8] Use of economic evaluation in local and national health care decision-making has been widely debated at health economics conferences in the UK and internationally.[i]

[i] For instance, the Health Economists' Study Group (HESG) and International Health Economics Associations (IHEA) have devoted entire sessions to this topic.

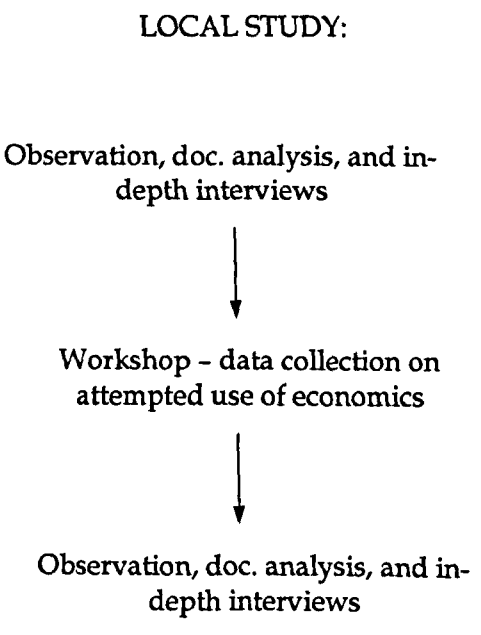
The overall aim of this thesis is to explore stakeholders' (local decision makers' and health economists') views and opinions about the use of economic evaluation. The use of economic evaluation has not been previously investigated in-depth using satisfactory methodology/methods, enabling decision maker's perceptions to be assessed. Further, health economists' views and opinions have not been solicited on this topic in a comprehensive way.

The focus is on the local level where decisions are made for the provision and commission of health care services to a community, for instance by a Primary Care Trust (PCT). Specific objectives of the research were:

1. To explore decision-making at the local level;
2. To investigate what factors decision makers perceive to be relevant to decision-making;
3. To ascertain whether economic evaluation techniques and practice is used in decision-making;

In relation to the local study, the sequence of events which occurred during the fieldwork is represented in Figure A:

Figure A: design of study



The initial stage of the project, which took place over a period of approximately twelve months, involved observation of a commissioning group for cancer care (the Cancer Group, or CG). This group was part of the PCT at the local level, although the geographical area has been anonymised. In addition to observation, documentary analysis of reports or papers brought to/referred to during the meetings as well as in-depth interviews were also conducted. Following this, a workshop on economics was held upon the request of the chair of the CG (and was delivered by an outside speaker). The local study differs from what appears, in a quantitative paradigm, to be a 'before and after' study, where an intervention is deliberately constructed, and the aim was not to try to determine whether changes resulted from this workshop. Instead, the workshop not only allowed the researcher to observe decision makers trying to prioritise but subsequently provided the opportunity to explore their feelings about the role of economics in further interviews, which had not been previously possible. Decision makers who were interviewed in this second round were selected to include those who had attended the workshop, but also those important to the process of decision-making as perceived by those already interviewed.

The work conducted with health economists comprised a parallel project, involving interviews with senior UK health economists, purposefully selected according to their role. The aim of these interviews was to explore their views of use of economic evaluation in local decision-making in the NHS. This is important since it is necessary to find out how far their views and opinions differ from local decision makers and to be able to reflect on the work undertaken by this group (as the main producer of economic evaluations in the UK).

The thesis is structured as follows. The first two chapters provide a literature review of the main topics in this thesis. Chapter one of this thesis explores the literature on the context and structure of National Health Service (NHS) decision-making. The first section of the chapter examines possible

organisational structures for delivering health care, and the background to the NHS in terms of policies, institutions, and actors. The second section then moves on to explore models of decision-making (grouped into broad categories of rational and non-rational models), which can be used to examine the behaviour of decision makers within organisations such as the NHS. The third section investigates rationing or priority setting, where decisions are made for a group of patients, and where the basis for decision-making can be implicit or explicit. The fourth section examines how research evidence might be used in decision-making (being closely related to the models of decision-making) and provides an interpretation for some of the findings in chapter 2. The final section of this chapter provides a conclusion, drawing together the main arguments.

Chapter two focuses on the literature on the use of economic evaluation in decision-making. The chapter begins by exploring recent developments in economic evaluation. Subsequent sections assess the use of economic evaluation, barriers to use, and incentives for greater use in health care decision-making. Findings are drawn from a systematic review, focusing on literature exploring use of economic evaluation at the local level. A methodological appraisal of the empirical studies examined is also provided. The final section provides a conclusion, summarising the main points of this chapter.

Chapter three presents the background to the approach taken in this study, as well as the specific methods used. The chapter begins by discussing the ontology, epistemology, and methodology associated with two research paradigms: positivist (typically used by economists) and constructivist/interpretivist (commonly used by qualitative researchers). It concludes that a qualitative approach will most successfully achieve the aims of this thesis. A modified 'grounded theory' approach was used to investigate the research question, combining observation of 'real-life' decision-making, documentary analysis, and in-depth interviews, some on more than one occasion, with those involved in decision-making for cancer services within one

area in the NHS. The chapter moves on to describe the methods used in this thesis to examine the views and opinions of health economists, as well as the qualitative analysis performed for the empirical work.

Chapter's four to six contain the findings from the empirical work. Chapter four focuses on decision-making at the local level. Here it is suggested that, although decision-making appears to be relatively clear and structured, there is an informal process revealing a far more complex system. With this in mind, chapter five investigates local decision makers' use of economic evaluation. Although the initial concern of the thesis was to examine the use of only economic evaluation in health care decision-making, the research conducted here goes beyond this and explores understanding of economic concepts and ways of thinking associated with economics. Chapter six examines health economists' perceptions of the use of economic evaluation by decision makers.

The final chapter of this thesis explores the main findings in the light of other research on this topic. This chapter is divided into six sections. The first section compares and contrasts views and opinions of decision makers and health economists' about local health care decision-making. This section further examines findings in relation to the organisational and decision-making models in chapter 1. The second section discusses the focus of this thesis: the use of economic evaluation; barriers to use; and incentives for greater use; according to decision makers and health economists and in conjunction with the literature in chapter 2. These findings have important implications for health care priority setting and the work undertaken by health economists, explored in the third section of this chapter. The fourth section evaluates the success of the studies on local decision-making and health economists. There are suggestions for researchers wishing to conduct any future work in this area in the fifth section. The final section provides a brief conclusion to this thesis.

This thesis makes an important contribution to health services research in two main ways. First, it provides insight into how priority decisions are made (or

equally not made, or avoided) in the NHS. Second, it provides further and unique evidence of the growing concern that 'technical' health economics approaches to priority setting do not fit well with the culture and management processes of the NHS.

Throughout this thesis, the terms meso and local level are used interchangeably, as are the terms priority setting and rationing. In addition, the term informant is often used to denote the individual researched in this thesis. On other occasions, they are labelled "decision maker" or "health economist", although it is acknowledged that these terms are limited and they are used only for analysis purposes.

Chapter 1: Decision-making in the NHS

This chapter covers a number of seemingly diverse areas, yet all enlighten different aspects of the context facing decision makers in the NHS. That is the purpose of this chapter. It begins by examining the organisational structures within which decision-making takes place. In this section, theoretical organisational structures are described and the current organisation of the NHS is both described and assessed in terms of these models. The second section of the chapter explains the different theoretical models of decision-making. The third section of the chapter looks at the nature of decision-making where the rationing of interventions is involved. Here relevant empirical evidence of decision-making in the NHS is examined in relation to the models of decision-making. The fourth section considers the nature of the use of research evidence in decision-making. The final section of this chapter provides a conclusion, drawing the main arguments together and exploring the differences in context between those faced in the NHS and those that form the basis of economic thinking.

1. Organisation of health care

1.1 Models

It is important to understand the models of health care organisation to be able to gain insight into the overall context and structure in which decision-making takes place. In this section, organisational models for delivering health care (or indeed any product or service) are commonly referred to as the market model,[9] the command and control model[9] (or hierarchical model[10]), and the network model.[9] Each is discussed in turn, although more than one of these models can exist at the same time.

a) Market model

A market is essentially an adjustment mechanism for demand and supply, freely permitting the exchange of goods and services between consumers and producers without the need for intervention from the Government.[11] The market adjusts using price signals (where prices determine the allocation of resources or production of goods or services) and, at a given market price, producers offer their goods or services for sale and consumers purchase these according to their desires.[12] Market equilibrium is reached when producers are able to sell all they want (to maximise their profits) and consumers are able to buy all they want (to maximise their utility or satisfaction).[12] These notions are present in Smith's famous 'invisible hand' theorem[13] which suggests that this situation occurs even though it is not intentional and consumers and producers have no knowledge of it (hence 'invisible').

A perfect market system, which describes an ideal (theoretical) system, delivers maximum consumer satisfaction within the available resources. The economy will be in a position of 'Pareto' optimality (named after the famous Italian economist), because it will be impossible to make one person better off without making someone else worse off.[14] However, this system can only work under certain conditions (Table 1.1).[11]

Table 1.1: conditions of a perfect market system

Assumption	Explanation
Certainty	Consumers know exactly what goods or services they want and where they can get them from
No (positive or negative) externalities[ii]	There are no 'spillovers' from production or consumption of commodities, since these cannot be accounted for in the market as everyone considers only the costs and benefits to themselves
Perfect knowledge	There is perfect knowledge of the market (in health care this implies that the patient is aware of his or her health status and the relevant treatment options)

[ii] An externality exists when one person's consumption of a good or service has an effect on another's.[14] An example of a positive externality is a household in a neighbourhood maintaining their garden, which has an (unintended) positive effect on those who see the garden (hence an increase in another person's utility). An example of a negative externality is pollution to a river, which harms the fish, and reduces the stock of fish for fishmongers in the area (hence a decrease in another person's utility).

Consumers act freely	The consumer acts in their own interest about what to consume (in health care, independent of doctors for instance)
Numerous, small producers with no market power	Competition occurs only on the basis of price and producers keep prices as low as possible to attract consumers (in health care this would mean that no one decision maker has power over another)

(Adapted from Donaldson and Gerard, p.21[11])

In practice, there are likely to be violations of the conditions in Table 1.1, leading to market failure.[15] For instance, monopolies or duopolies have considerable market power. There are five major violations of the conditions for perfect markets in health care (Table 1.2). Arguably, the case for market failure in health care is greater than in other markets (for example, food) because of limitations in knowledge about health care among typical citizens (hence the role for doctors or specialists in health care).

Table 1.2: violation of axioms of perfect markets in health

Axiom	Violation
Certainty	Although some items of health care consumption (such as purchasing of spectacles once vision becomes deteriorated) can be planned, many items cannot be planned, since deteriorations in health are often sudden or unexpected
No externalities	There are various positive and negative externalities in health, which mean that others benefit from people's consumption of health care
Perfect knowledge	For minor common ailments, such as colds, consumers are likely to be aware of their health status and treatment options. However, for more acute conditions, consumers are unlikely to be aware of their health status and the treatment options available (for instance, in the case of treatments for cancer). In addition, knowledge of the health care market is likely to be less than knowledge of other more commonly used markets (such as food)
Consumers act freely	Doctors are placed in a position of providing expert advice to patients, because of a lack of perfect knowledge of health care. The demand for health care can be influenced by the supply of care
Numerous, small producers with no market power	Entry to the market for health care is guarded by requirement for licenses for doctors and other medical professionals to practice

(Adapted from Donaldson and Gerard, p.20-25[11])

There are ways of overcoming these problems within a market-based system. The market response to uncertainty in health care is to develop insurance

mechanisms to account for the financial costs of ill health. However, even then, market failure can arise from two sources: moral hazard and/or adverse selection.[11] Moral hazard arises because insurance reduces the cost of treatment at the point of consumption and so the individual might have less incentive to take care of themselves in order to prevent ill health.[15] Moral hazard can be countered, to some extent, by the use of co-payments, where the individual pays a certain amount of the supplier's charge. In practice, however, total health care expenditures may not change if doctors provide similar total levels of service but to a smaller group of patients who can afford it.[11] Adverse selection occurs because purchasers of insurance tend to be more informed of their risk status than insurance companies.[15] In a competitive market, premiums could be set to reflect the general health risks of the population, but this may lead to two groups being left uninsured: individuals with lower than average risks who find the insurance premium too high and so leave the market; and individuals with a higher risk (and are subjected to a tailored insurance premium or 'experience rating') who find the premium too high and/or cannot obtain insurance.[15] This is not an efficiency problem, but an equity problem. However, adverse selection can also be seen as presenting an efficiency problem because of caring externalities (or the notion that individuals care about the health status of others and not just themselves). An individual's well being could therefore be affected by knowing that other individuals are not receiving adequate health care.

An alternative version of the market model is called the quasi-market[9] ,which is more likely to be used in health care in developed countries. Quasi-markets differ from conventional markets in that: they tend to be non-profit making and compete for public contracts; purchasing is often through a single agency; and consumers might be represented as agents rather than representing themselves.[16] In health care, a quasi-market could involve the Government retaining purchasing of services, but separating purchasers from providers and encouraging competition between providers of care for service delivery.[9] The Government provides money to purchasers of health care, who then purchase

on behalf of consumers or patients from the producers of health care. However, there has been little discussion so far on the exact role for the Government in quasi-markets, an important omission since the Government is integral to the quasi-market.[17] It is not known for instance, whether the Government should intervene to ensure the market operates appropriately. Nevertheless, because there is a more controlled market situation, some of the problems associated with less restricted markets are potentially alleviated.

b) Command and control model

For Coase[18] and Williamson,[19] the fundamental question was: 'why do firms exist if the pricing system provides all of the co-ordination necessary for economic activity?' Coase argued that price-guided co-ordination is not costless, as typically assumed. It is proposed that there are transaction costs associated with the acquisition of information about prices and the process of exchange. Transaction costs can be defined as "any activity which is engaged in to satisfy each party to an exchange that the value given and received is in accord to his or her expectations" (Ouchi, p.130[20]). From a transactions cost perspective, markets fail when the price mechanism does not allocate resources effectively and the costs of completing contracts become too high (hence promoting the role of an organisation).[20] The market is only efficient when there is little ambiguity over individual performance.[20] Williamson has helpfully categorised market failure into "human factors" (bounded rationality and opportunistic behaviour) and "environmental factors" (uncertainty and small numbers) [Williamson, p.21-40[19]]. Bounded rationality refers to limits to the amount of information reasonable individuals can store (discussed further in section 2.1). Opportunistic behaviour is an extension of self-interest to allow for strategic behaviour, which can involve selecting or distorting information, or making calculated promises about future behaviour.[19] Environmental factors include uncertainty [which arises because decision-making is not "deterministic" (Williamson, p.23[19]), since it cannot be specifically planned and mediated before-hand] and small numbers (referring to a less than competitive situation due to a limited number of buyers of sellers). However, only a

combination of two or more of the individual attributes in the factors can cause market failure.[19] For instance, opportunism itself does not imply that markets fail and it is the opportunism together with small numbers that can lead to the problem of bilateral monopolists.

Hierarchies can exist in an organisation, as an attempt to reduce transaction costs. Firms will organise themselves internally when the transaction costs are lower than when activities are organised through markets. Here the Government is a large organisation, perceived as being bureaucratic in nature and operating through command and control. A bureaucracy has been defined as "a corporate body which mediates the relationship by placing a value on each contribution and then compensating it fairly" (Ouchi, p.130[20]), where the relationship is between the organisation and its workers. This distinguishes bureaucracies from markets, where transactions are mediated by the price mechanism.[20]

In health care, externalities are strong arguments for the Government's role in resource allocation. Positive externalities may accrue, as in the case of vaccinations, as vaccinating one individual prevents transmission of the virus to others.[11] In such situations, there is a role for the Government to subsidise or provide, free of charge, immunisations, since this would need to be delivered on a national scale.[14] In addition, people might care about other people's health care needs as well as their own, which can be seen as a positive externality.[14] For instance, some people would have a greater utility from knowing that a life-saving technology was available not just to them, but also to others who could not afford to use it. Here, the market response would be to distribute resources efficiently, and then employ the right amount of taxes and subsidies to redistribute income.[14] However, the problem is that it is virtually impossible to establish the appropriate level of taxes and subsidies.[14]

Although bureaucracies are typically introduced when markets fail or need supplementing, they are not always a perfect solution. Bureaucracies can fail

when "ambiguity of performance evaluation becomes significantly greater than that which brings about market failure" (Ouchi, p.134[20]). The final part of this section discussed an alternative model.

c) Network model

A network has been defined as:

A specific type of relation linking a defined set of persons, objects or events...The set of persons, objects, or events by which a network is defined may be called the actors or nodes. These elements possess some attribute(s) that identify them as members of the same equivalence class for purposes of determining the network among them.
(Knoke and Kuklinkski, p.175[21])

Examples of networks include labour unions[20] and health care systems comprising interactions between doctors, nurses, and patients[21]. Differences between networks can exist with regard to the way they are internally organised. Williamson has defined networks as "wheel" or "all-channel". A wheel, often referred as a hub and spokes system, refers to a series of hierarchies controlled by a single unit. In an all-channel network, all bodies are connected to each other in the organisation, so that there is no hierarchy.[22]

Networks emphasise the organisation of social relations and the behavioural implications for individual units and for the whole network. Essentially, networks rely upon relationships that foster trust and co-operation.[9, 20] Trust has been defined as the expectation that a person or institution will respond in an appropriate manner, consistent with their roles and responsibilities.[23] Trust appears to be particularly important when there is uncertainty and the level of risk is high, because there needs to be a minimum level of understanding in such circumstances between co-workers.[24]

In health care, there is a need for trust to exist between the purchaser and provider of health care, where they are separated from each other, since there are likely to be problems in measuring and monitoring quality of care.[25] This means that purchasers might rely on information relating to reputation and

trust that providers will deliver appropriate care when assessing provider performance.[25] According to Arrow, using a trusted agent can economise on transactions costs,[26] although there appears to be little investigation into the role of trust in modern (neo-classical) economics[25] or the role of networks.

However, networks do not appear to offer a complete solution to the problems presented by markets or hierarchies. Williamson[27] suggests that networks are unstable in the long run because of co-ordination problems. He argues that because decisions require consent, the decision-making process is likely to be costly.[27]

It is difficult from the arguments presented so far to conclude that one model of health care organisation is better than another. In reality, all are likely to face problems. As evidenced by a typical market-based system, the US, there are problems associated with inability for some members of the population to afford basic health care and increasing health care costs. In the UK, which might be seen as a traditionally command and control system, difficulties are associated with long waiting lists, rising costs to the Government, lack of patient choice, and a perception of rationing.

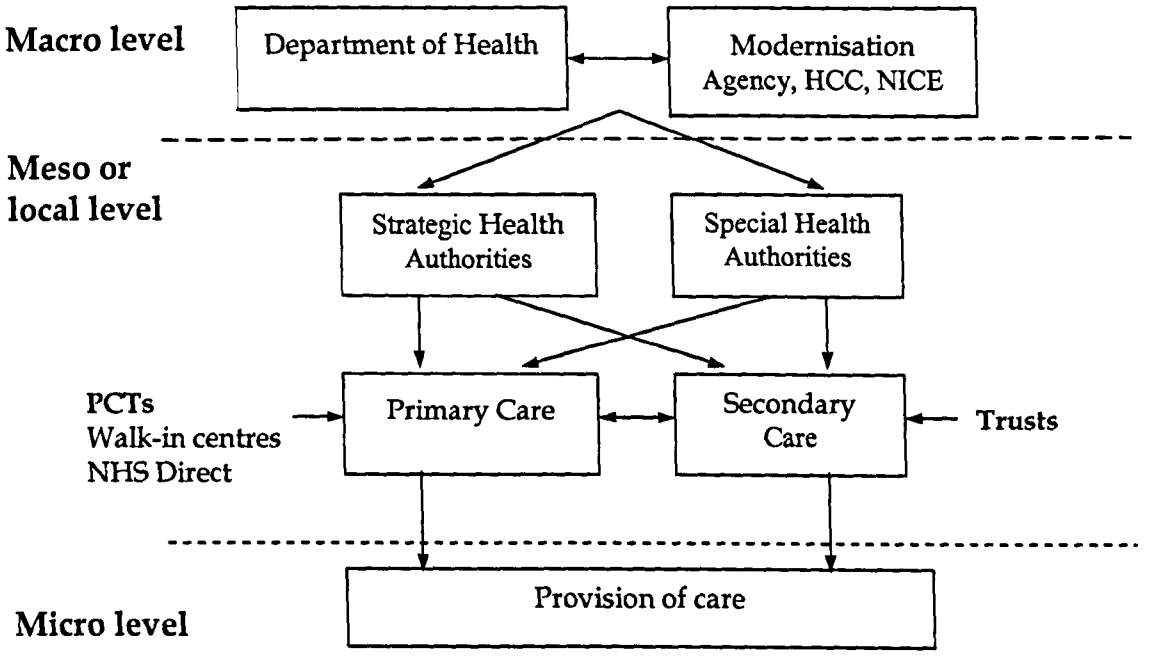
1.2 Overview of the NHS

The organisational models are, however, theoretical. This section explores their applicability to the NHS, beginning by describing how health care is typically organised in the NHS. Although there are variations in England, Wales, Scotland, and Northern Ireland,[28] the focus here will be on England. This section first discusses the organisations and actors involved at various levels of decision-making. It then moves on to examine the corresponding applicability of the models of organisation. The final part of this section addresses agency relationships, which are crucial to the understanding of any health care system.

a) Organisation and actors

The NHS provides health care for all citizens, with the aim to achieve the highest level of health for citizens, within available resources.[29] There are three commonly used terms in the literature which describe the levels in health care decision-making (the macro level, the meso level, and the micro level[30,31]) and these relate to the organisation of health care (Figure 1.1).

Figure 1.1: overview of the NHS organisation in England



(Adapted from www.doh.co.uk)

The macro level

Although the macro level is not the focus of the empirical research presented in this thesis, it is important to understand the way in which decisions that are made 'higher up' in the hierarchy might affect policies or actions taken at either the meso or micro levels. The Government, through the Department of Health (DoH), is responsible for leading the direction of the NHS. Essentially, the health service is a national service and is accountable to Parliament.[32] At the macro level, decisions are made by politicians to determine the level of resources for the health care system. Currently, the DoH has decided upon five

specific clinical priorities, in cancer, Coronary Heart Disease (CHD), mental health, older people, and children.[33] The general direction in which policy should develop is contained in the recent White Papers and subsequent acts of Parliament.[34] Also at the macro level, the Modernisation Agency advises NHS managers and clinicians to deliver improvements (or modernisation) to their services[29] and they work directly with the DoH.

Two other agencies are also part of the macro level and have had increasing importance in the last few years: the National Institute for Health and Clinical Excellence (NICE) and the Health Care Commission (HCC). In England and Wales, NICE has the role of assessing drugs and medical devices based on evidence about their clinical effectiveness and cost-effectiveness.[35] One of the main reasons for establishing NICE was to curb "postcode prescribing" (patients in different geographical areas receiving different treatments or services based on their location).[35] As from April 2005, NICE has also taken on the role of evaluating public health interventions. The HCC is essentially an inspectorate, since it is responsible for evaluating the performance of NHS institutions and monitoring adherence to Government policy, such as the National Service Frameworks (NSFs), which specify good practice in different speciality areas. In addition, the HCC is responsible for monitoring and controlling a 'star system' whereby Trusts and PCTs are awarded points (from zero to three) depending on their performance.[36] Process indicators, such as compliance with targets, largely determine the number of awarded stars. The targets, set out in the NHS Plan,[37] are in terms of meeting required clinical standards, such as the number of hospital beds and medical staff, as well as maximum waiting times. For many interventions, waiting lists are used to determine the order in which patients receive services. Patients needing certain procedures or interventions within the hospital are put onto a list and called forward to receive the intervention when there is a space for them. Certain waiting time targets exist for patients with urgent conditions. For instance, the waiting times for diagnosis and treatment for suspected cancer cases, as specified in the Cancer Plan (2003),[38] are as follows:

- Maximum two-week wait from an urgent GP referral for suspected cancer to date first seen for suspected cancers by end of 2000;
- Maximum one-month wait from urgent GP referral to first treatment for children's cancers, testicular cancer and acute leukaemia by end 2001;
- Maximum one-month wait from diagnosis to first treatment for breast cancer;
- Maximum two-month wait from urgent GP referral to first treatment for breast cancer by 2002;
- Maximum two-month wait from urgent GP referral for suspected cancer to first treatment for all cancers by 2005;
- Maximum one-month wait from diagnosis to treatment for all cancers by 2005.

The meso level

At the meso level, decisions are made on behalf of the local population about the amount of money that should be assigned to programmes or to specialties. Strategic Health Authorities (SHAs), which typically cover an average population of 1.5 million[39], develop strategies for the NHS and performance manage their local NHS organisations, involving overseeing activities among PCTs and Trusts (or hospitals).[32] Special Health Authorities (Special HAs), of which there are almost twenty in England, including the National Blood Authority (NBS), provide health services to the whole of England, rather than specifically to a local community.

Below the SHA and Special HAs, Primary Care Trusts (PCTs) are responsible for providing and commissioning local services, as well as developing primary and community health services and improving health in their areas[32] (where an area typically consists of about one hundred thousand people[40]). PCTs generally commission from secondary care Trusts; they are responsible for ensuring that services they offer are delivered to a high quality.[29] Typically a PCT is run by a board, including a chairman, chief executive, finance director,

director of public health, and non-executive directors or lay people.[32] The day-to-day operation of the PCT is the domain of a professional executive committee, comprising a majority of professional members such as GPs and nurses, and members from the PCT.[32]

Formal policy at the local level is largely guided through Local Delivery Plans (LDPs), which focus on the health and social care priorities set out in the Priorities and Planning Framework (PPF). The PPF covers a three-year period and identifies national priorities and targets that organisations need to incorporate into their local plans.[41] The PPF for the period 2003 to 2006 specifically identifies priorities to include: improving access to all services (through better emergency care, reduced waiting, and greater patient choice); focusing on improving services and outcomes (in the five clinical areas mentioned previously); and reducing health inequalities.[41] More generally, the PPF formally states the need to: "focus on priorities,[...] extract the maximum value from every pound, be prepared to change old practices, be creative and take uncomfortable and difficult decisions in the drive to improve quality and respond to people using services" (Nigel Crisp, Chief Executive of the NHS[41]). At the local level however, PCTs have the freedom to develop local, non-PPF, priorities.

The PCT appears to be fundamental to the process of local health care delivery. Its responsibility is reflected in the fact that, as from April 2003, PCTs have been entrusted to control up to 75% of the NHS budget,[9, 32] although it would be surprising if this were achievable to the same degree in all localities. The purpose of entrusting the PCT with a large proportion of the budget is to ensure that staff in contact with patients can influence how resources are used.[32] Indeed, although PCTs are required to 'break-even', they can retain any surplus in their budget, which can be spent on services or facilities for their local community.[9] However, it has been suggested that PCTs do not have sufficient resources to manage the organisational change that they have been subject to.[40]

At the local level, two new providers of care are NHS direct and NHS walk-in centres. NHS Direct is a twenty-four hour telephone service for nurse advice and health information.[29] Nurses use a computerised decision-support software in order to triage callers: to self-care; to contact their GP immediately or later; or to attend Accident and Emergency (A&E).[42] However, whether NHS Direct provides an alternative to traditional GP-based services is questionable. Analysis of routinely collected data during a recent influenza-like illness epidemic suggested that there was no impact on the number of GP consultations, in relation to the illness.[43] The appropriateness of triaged decisions in NHS Direct has also been queried.[42]

Walk-in centres provide physical access to medical advice without an appointment[29] during convenient hours (usually 7am to 10pm every day) and in a convenient location.[44] The dual purposes of the centres are to address unmet need in primary care and to address issues of access.[45] The centres provide information and treatment for minor conditions, and are led by nurses.[44] However, there appears to be limited evidence that service delivery in walk-in centres is planned in response to needs.[44] Although Le Grand views the creation of walk-in centres as a form of competition to GP based services[9], they do not appear to attract a different population from those visiting GPs[44] and there has not been any evidence of impact on out-of-hours services.[46] In this sense, walk-in centres may be no more economical than GP based services, particularly because consultations in the former tend to be lengthy.[44] Despite these concerns, a recent postal survey has shown that the majority of local providers are in favour of walk-in centres, although GPs in particular tend to be concerned with the continuity of care provided there.[45]

The micro level

At the micro level, health care professionals, such as GPs and hospital doctors, make decisions about the treatment of individual patients,[30] inevitably involving decisions about who to treat and what treatment or services they should receive.[34, 47] GPs and hospital doctors are typically direct providers of

services who determine, in conjunction with the patient, the direction of treatment.[32, 48] Furthermore, groups of GPs have clinical and financial responsibility, since they must make prescribing and referral decisions within their budget.[34]

b) Market, hierarchy, or network?

All three models of organisation appear to be used in the NHS. The command and control model "dominated both network and market" during the early years of the Labour Government (Le Grand, p.148[9]) and the hierarchical nature of the health care system is also reflected in the levels of decision-making in Figure 1.1. Indeed, five clinical priorities (defined previously) have been set at the national level and are a major focus in formal PCT decision-making (in the LDP). In addition, there is a strong emphasis on meeting national targets, which are used as a basis to rate the quality of Trusts and PCTs. A comparison has been made between the feudal system, of knights being delegated property in return for fighting for the king, and the need to meet targets by senior managers in the NHS.[10]

However, the command and control system alone does not fully explain the organisational structure of the NHS. A market based system was in place during the internal (or quasi-) market, set up by the Conservative Government in 1991, which categorised HAs and GP fundholders (who were essentially budget holders) as the purchasers of health care and independent Trusts as providers of health care (hence the 'purchaser-provider split').[9, 49, 50] The role of purchasers was to assess health requirements and purchase services to meet these requirements, whereas the role of providers was to deliver services against contracts or service agreements.[50] Although the internal market was largely abolished, or, at least, pushed somewhat backstage by the current Government,[9] the purchaser-provider split has been retained (PCTs became 'commissioners' and contracts became long-term agreements[9]). This might explain why PCTs have been specifically compared to Managed Care Organisations (MCOs) in the market health care system in the US,[51, 52] since, in

essence, both are free-standing bodies with responsibility for providing community health services.

Currently, there is a drive towards devolving power and responsibility to patients,[53] further suggesting a more market based system of health care delivery. PCTs are coming under increasing pressure to cope with greater market incentives.[54, 55] Patient choice has empowered patients to demand the type of treatment they want, as well as when and where they receive it.[54] In theory, patients are able to choose a Trust with a lower waiting time or better accommodation.[28] There is a problem however in that those who require the most care may well get the least, because the sickest and worst-off tend to lack substantial knowledge of the organisation of health care in order to make informed decisions.[28] The Government has also advocated consumer groups (consisting of patients, users, and carers) to be involved in making decisions,[56] again implying greater power among consumers.

Market pressures have also arisen through financial incentives created by these initiatives. Payment by results mean that Trusts are being funded on the basis of the work they undertake,[32] which implies greater pressure for them to 'compete' by 'producing more'. This, however, only takes into account the work, which is being undertaken and does not reflect other aspects such as the quality of the services being offered by the Trust. In addition, the scheme of Private Finance Initiative (PFI) involves the private sector raising money on the Government's behalf, in return for a contract to design and build a hospital and operate the facilities for thirty years or more.[57] This scheme has been criticised for reducing the comparative advantage of public sector procurement[57], creating increased costs and therefore being potentially detrimental to patient's quality of care, which could be reduced as a result of trying to save money.

Perhaps the greatest pressure on PCTs is the Government's idea for Foundation Trusts.[58, 59, 60] Foundation Trust status allows NHS hospitals and PCTs to be locally, rather than nationally, accountable and thereby have increased freedom

to control their level of spending and make specific decisions for their community. They will be, essentially, driven by the demands of PCTs, as well as patients and regulators,[28] although they are still obliged to follow national policies. Potential disadvantages of Foundation Trusts include greater bureaucracy because of new accountability arrangements[61] and creating the risk of a "two-tier" health system, where Foundation Trusts improve in contrast to non-Foundation Trusts.[62] This questions whether Foundation Trusts can really generate greater quality of patient care and points to potential discrepancies in care of patients in different Trusts.

Although together the command and control and market models describe some elements of the current system quite well, there also appear to be elements of the network model. Local health strategies, as defined in the LDP, provide a means of translating national targets into practice, through the integration of various institutions and actors.[32] As suggested in Figure 1.1, PCTs and Trusts decide the delivery of care most appropriate to their local population. Networks also exist between Trusts themselves and between various groups operating under the PCT.[9] In addition, clinical networks provide a framework for organising and developing local clinical services.[63] These networks can be service focused, in relation to specific diseases (such as cancer), specific specialties (such as cardiology),[63] or client grouped (such as older people). The Calman-Hine report on Cancer Services signified the beginning of a network in cancer care.[64] Cancer networks are intended to provide expertise in cancer care, ranging from primary care through to cancer units in hospital. So far, thirty-four cancer networks have been established in England. There are also networks in CHD and vascular surgery. Clinical networks have the potential to alleviate traditional boundaries between primary, secondary, and tertiary care, as well as providing configurations that are likely to be more closely aligned to the patient's pathway (their experience of care), rather than to the institutions.[63] Clinical networks have the benefits of being clinically focused, collaborative, and flexible, responding well to environmental change.[65]

c) Agency relationships

Although there are different organisational structures in any health care system, agency relationships between decision makers can be applicable to any model.[66] The principal-agency relationship exists because the principal is ill-informed about some area and therefore employs an agent with specialist skills or knowledge to make decisions on their behalf.[67] The formal principal-agency theory applies to the following situation:

> *One individual, called the agent and denoted A, must choose some action **a** from a given set of actions {**a**}. The particular outcome x which results from this choice depends also on which element from some given set of states of the world, {θ}, actually prevails at the relevant time, so that uncertainty is intrinsic to the situation. The outcome x generates utility to a second individual, the principal, denoted P. A contract is to be defined under which P makes a payment y to A. A's utility depends both on this payment y and the value of the action, **a**.*
> (Rees, p.3[68])

The challenge for the principal is to devise incentives to ensure that the agent makes decisions in the principal's best interests (since the principal cannot observe the agents actions, resulting in information asymmetry).[68] Both principal and agent are assumed to maximise their own utility or satisfaction. The utility functions, which characterise the important factors of principal and agent, are assumed to be independent of one another and represented as[68, 69]:

P utility function: $u = f(x,y)$

A utility function: $v = f(y,a)$

If the principal and agent's utility functions coincide, the agent will choose an action which maximises their utility as well as the principal's, although this might not necessarily be the case. Both principal and agent are assumed to be risk neutral or risk averse (so that they do not want to take risks).[70] Furthermore, it is assumed that both agent and principal have the same beliefs about the probability of the state of the world, although, in practice, the agent may have better information than the principal.[68] An additional assumption of

the model is that the agent's outcomes (dependent on θ and a) are observable, although in practice this will be difficult to achieve.[70]

In health care, there are three clearly discernable principal-agency relationships between: 1) doctors and patients; 2) decision makers and society; and 3) decision makers as agents for other decision makers in an organisation, as in commissioning relationships. Firstly, patients act as the principal and employ the doctor to act as an expert on their behalf in making decisions about the consumption of health care.[71] There is information asymmetry between doctors and their patients in that doctors have more expert knowledge. In a perfect agency relationship the doctor would act entirely as if he/she was the patient. In practice, however, there is likely to be interdependence between the patient's and the doctor's utility function[72] implying that the doctor includes some part of the patient's interests in his or her own objectives, but also has his or her own interests to pursue (such as financial interests), which may conflict with the interests of the patient.[69] However, whether this is the case remains a contested issue among some economists.[69] Secondly, there might also be a case where decision makers act as an agent for the wider society given scarcity of resources.[71] In such cases, decision makers take a societal perspective and make decisions for groups of patients. Thirdly, there are likely to be agency relationships between decision makers themselves, as in commissioning relationships, for instance between PCTs and Trusts, or managers and clinicians. Few studies, however, have used principal-agent theory to explore commissioning relationships in the NHS, with the most extensive research to date being conducted by Baxter.[66] This study found that there was a weak link in the principal-agency chain of commissioning and this necessarily led to non-compliance with decisions.

2. Theories of decision-making

So far, the discussion has shed light on the complexity of the organisation of health care at the local level, in terms of the actors involved, their formal

relationships, and the possible organisational structures which decision makers might operate in. However, it is also important to explore the behaviour or decision-making of individuals *within* organisations in order to find out how decisions might be made. There are two broad models of decision-making that can be used to study NHS decision-making: rational and non-rational models. Rational models include classic rationality (as assumed in neo-classical economics), alternative rationalities, such as game rationality, and other 'rational' models which focus on the organisation rather than the individual, as in the incremental model of decision-making[73] and pluralism (or political model of decision-making).[74] In contrast, the anarchy or garbage can model[75] assumes the alternative case of non-rational decision-making. Apart from the classic model of rationality, the models here do not prescribe how decisions ought to be made, but are largely descriptive. The discussion here is also mainly theoretical and section 3 will focus on how decisions are actually made in the NHS.

2.1 Rational models of decision-making

a) Classic rationality (in neo-classical economics)

Economists, on the whole, assume rationality.[76] Although rationality might mean something different in an everyday sense[iii], it has a specific meaning in the theory of choice, which is the basis of most neo-classical economic theory. Smith[13] suggested that rational self-interest drives man to want to uphold the Government because he is then free to pursue his own activities and leave the running of the country to the Government. In this sense, self-interest is not seen as negative, because it facilitates an optimal working of the economy. However, this definition does not explain the specific meaning of rationality in neo-classical economics, and economists later conjured the term rationality rather than self-interest. Rational models of decision-making regard the household as a unitary decision-making body that makes decisions for all its members

[iii] The standard dictionary definition of "rational" refers to individuals as being endowed with reason or having a sound judgement.

about what they do and what they will each consume.[77] Thus, the household is assumed to be a single decision maker with shared interests.

It is assumed that an individual has a specific set of objectives which they will pursue.[76,78] For example, an individual would like to buy a bundle of commodities which he or she can afford and which makes him or her feel most satisfied (in terms of utility).[76] The objective is to maximize this utility (U) or bundle of goods yielding utility (X) subject to the constraints, which, in this case, could be income (Y):

Maximise $U(X_1, X_2, \ldots)$, *subject to* Y

Economists typically assume the specification of the objective function from other disciplines. For example, on the basis of some human psychology, individuals are assumed to maximise satisfaction.[79] The accuracy of such descriptions is rarely tested however. For this model to hold, there are three axioms of behaviour (reflexivity, completeness, and transitivity) that must be satisfied (Table 1.3).

Table 1.3: rational choice axioms of behaviour

Axiom	Explanation
Reflexivity	Assumes any bundle of good or service is always as good as itself. So, for bundle X, $X_i \sim X_i$ (where ~ means indifferent between the bundles, and i =1,..n)
Completeness	Completeness means that any two bundles can be compared and ranked. Thus, for X_i and Y_i, either $X_i \geq Y_i$, or $Y_i \geq X_i$ or the consumer is indifferent between the two bundles, in which case $X_i \sim Y_i$
Transitivity	Transitivity means that when one bundle of good or service, X, is preferred to another, Y, and Y to Z, then X should be preferred to Z. Hence, if $X_i \geq Y_i$, and $Y_i \geq Z_i$, then $X_i \geq Z_i$

(Adapted from Varian, p. 35[78] and Hargreaves Heap, p.6[80])

These axioms suggest individuals act rationally: they always choose what they most prefer, preferences are complete (so that they are never unable to chose between two options) and preferences are transitive. Thus, one test of

rationality used in economics is whether individuals are willing to pay more for commodity A than commodity B, if A is preferred to B.[81] These axioms of behaviour however have received criticism from both within and outside economics for failing to reflect how individuals make decisions in practice.[82] In particular, economists have recognised that the axiom of completeness might not hold in individual health care decision-making, with research suggesting that respondents to choice-related questionnaires have tended to 'construct values' in response to questioning, rather than reporting previously formed preferences.[83, 84,85] For instance, using a Discrete Choice Experiment (DCE),[iv] Ryan and Miguel[84] carried out a test to compare preferences for three different goods (a supermarket, dentist consultation, and bowel cancer screening) and found that for health goods in particular, preferences were constructed as respondents completed the exercise. This, they concluded, occurs because people are not familiar with making choices for health care. Similarly, Shiell *et al*[83] found that during re-interviews, one-third of respondents (comprising staff and students from a University) deliberately changed their answers relating to preferences for full health and two chronic health states. It appeared that they were encouraged to reflect on the values they had given previously and adjust their preferences. Although the construction of preferences might be inconsistent with economic theory, it has been said that this does not "threaten economic theory", since "no reasonable person would suppose any definition of rationality to be universally and exactly defined" (San Miguel *et al*, In Press[85]).

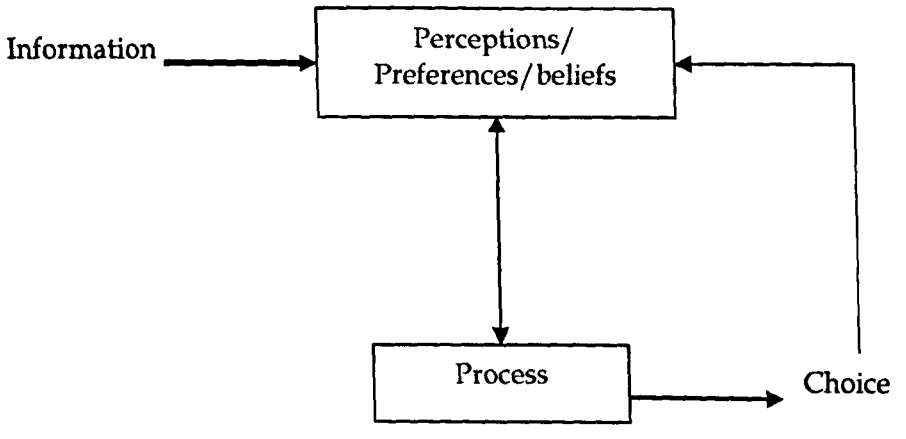
The transitivity condition has also been subject to criticism through alternative theories about how individuals behave, including regret theory and prospect theory. Regret theory offers an explanation for intransitive preferences. Both Bell[87] and Loomes and Sudgen[88] offered definitions of regret associated with the dissatisfaction when comparing the outcome for an action with the outcome for a different action. For example, an individual might regret not taking an umbrella when it rains and hence getting wet. The utility function would be

[iv] This technique attempts to measure the extent to which an individual values a good or service, depending on 'levels' associated with its characteristics (or attributes).[86]

modified to take account of the effects of regret, using the value of the outcome reached (by not taking an umbrella) and the value of the outcome that would have been reached (had an umbrella been taken).[89] The authors suggest that individuals do not maximise their expected utility, but attempt to minimise their anticipated regret. Prospect theory,[90] which attempts to describe decisions under uncertainty, shows that people's attitudes toward risks concerning gains may be quite different from their attitudes toward risks concerning losses. Prospect theory differs from expected utility theory because probabilities are attached to particular outcomes, treating preferences as a function of decision weights.

There do appear to be limitations of classic rationality, which economists are reluctant to consider. Typically classic rationality focuses on the relationship between information and choice (Figure 1.2). Peoples preferences are largely assumed to conform to the axioms of behaviour (as in Table 1.3).[91] Similarly, the stages leading to a decision or choice (*i.e.* the process) are largely ignored, although, in practice, the decision-making process might affect preferences. However, since rational models are generally concerned with individual decision-making, it is unsurprising that process is not seen as important.

Figure 1.2: limitations of the rational model



(Adapted from McFadden, p.74[91])

Indeed, classic rationality is unlikely to reflect 'real' decision situations, because of its reliance on the unrealistic assumptions of there being a single decision maker, with a defined set of objectives, and whose preferences correspond to the axioms described previously. Furthermore, classic rationality fails to take into account lack of consensus over goals, constraints on time and financial resources, organisational problems which limit rationality, and lack of information to make informed choices.

Although experiments have shown that a substantial number of people exhibit systematic patterns of choice that violate predictions of utility theory, this has not impeded the adoption of utility maximisation as the main model of behaviour of individuals by economists.[92] Instead, it has been suggested that the experimental evidence showing violations of utility theory simply reveal where the approximations falter and is useful for this purpose.[92]

Classic rationality models are likely to be a good starting point for analysing decision-making and are relatively intuitive to understand, since some factors (such as behaviour) can be kept constant. With such a view of the world, economic evaluation would naturally be used by decision makers because it provides information for rational decision-making. Although this might not be the case, economists have been unwilling to abandon the model, as this would involve a new way of thinking - suggesting a possible reason why it appears that although some economists have adapted rationality, they have still assumed it exists. Favouring rationality for these reasons, however, may not provide sufficient justification since economists are ignoring 'real' life situations. In order to invoke economists to replace classic rationality, it would be necessary to show that it is not useful for the purposes it is being used.[92] Although this may have been shown, economists have been reluctant to abandon the model.

b) Alternative rationalities

Rather than assuming the strict version of rationality, there have been various departures from the definition, particularly over the past fifty or so years.[93, 94]

Perhaps the most prominent of these departures is the notion of bounded rationality, developed by Simon,[93] which suggests that individuals adopt short-cut devices to decision-making and hence rationality is "bounded" because of informational and computational limits. Bounded rationality has been defined as "intendedly rational, but only limitedly so" (Simon, p. xxiv[95]). Although bounded rationality still assumes that decisions begin with specific goals and objectives and that there is clarity over goals, it takes into account physical limits on the ability of individuals to receive and store information, and also language limits because of the inherent inability of all individuals to articulate their knowledge or feelings in a way which is understood by others.[95] Decisions are therefore characterised by "satisficing", or selecting a solution that meets a minimum standard of acceptance, rather than by maximising.[96] Satisficing is not necessarily undesirable - it actually resolves problems by producing solutions that are satisfactory, as opposed to optimal but unobtainable.

Although there is no complete theory of bounded rationality, three processes that models of bounded rationality can take are simple search rules, simple stopping rules, and simple decision rules.[97] The first refers to a process of search whereby a piece of information is acquired and the process is continued up to some (undefined) point. The second refers to terminating search by simple stopping rules, such as to choose the first solution that satisfies an aspiration level. Searching for a radio station is a good example of this process. An individual will find it hard to optimise his or her choice, because it is not possible to search for all stations at the same time and most individuals will therefore stop searching upon hearing a song they like, or, at least, do not mind listening to.[96] Finally, simple decision rules refer to choosing the most important solution from many.

Since Simon's original work, further definitions of rationality, including game rationality and process rationality, have emerged. These are, again, believed to conform more closely to actual human behaviour than rationality.[98] Firstly, game rationality refers to the tendency of individuals within organizations to

act in relation to each other and co-operate to fulfil individual objectives.[98] A game is a situation where the actions of one person affect the welfare of another and vice versa.[80] This can lead to cooperation or rivalry. The essence of game theory is that individuals will try to predict what others will do in response to their actions, and then optimise on the basis that others are thinking the same. An example of game theory is "Prisoner's Dilemma".[80] Here, two suspects are taken into custody and separated. The police are certain that they are guilty of a crime, but there is inadequate evidence. They point out to the prisoners that there are two alternatives: to confess or not to confess. If they both do not confess, they will both receive minor punishment, whereas if they both confess they will be prosecuted. But, if one of them confesses and the other does not, the confessor will receive a lenient treatment, whereas the other will receive a harsh treatment. The 'payoffs' are as in Table 1.4.

Table 1.4: example of prisoners dilemma

		Prisoner 1	
		Not confess	*Confess*
Prisoner 2	*Not confess*	1 year each	10 years for 2 and 3 months for 1
	Confess	3 months for 2 and 10 years for 1	8 years each

(Source: Hargreaves and Heap, p.99[99])

Here, there is a two-player one-shot game (the game is only played once). It is also a non-co-operative game since the prisoners cannot collaborate to make an agreement. Confessing is the strictly dominant strategy, since whatever prisoner 1 or 2 does, each does better by confessing. Game theoretic approaches go well beyond individual decision-making, towards the pluralistic models, discussed in a later section. However, game theory does not completely agree with pluralism, since the basis of game theory is the individual rather than the organisation.

Further, individuals might be less interested in the final outcome of the decision than the way in which the decision is reached. Process rationality refers to the act of decision-making conveying utility or disutility (displeasure), rather than the decision itself.[98] The existence of process rationality has been empirically tested by Wailoo and Anand.[100] Here, six dimensions of procedure in relation to health care rationing were evaluated using a postal survey of the general public (at three different levels: the clinical level, local level, and Government). These dimensions were: "voice", or involvement in decision-making process, "consistency" of decision-making (in terms of procedural consistency), "absence of vested interests" or disproportionate balance of power, "transparency" of decisions made in terms of given rationale, "reversibility" of wrong decisions, and "accuracy of information". The authors found that the majority of respondents believed procedures, or the way decisions are made regarding health care rationing, are important, although the degree of importance varied according to the type of procedure and decision-making context. For instance, respondents felt that it was more important for national, rather than local, rationing decisions to be made in consultation with the public.

However, these more sophisticated approaches to rational decision-making, such as bounded rationality, game rationality, and process rationality still assume the general approach taken in neo-classical economics and therefore do not represent a highly significant departure. They presume that individuals are rational and that they have an objective to pursue. Economic evaluation would still be perceived as useful to these rational, albeit not neoclassical, decision makers, in helping them achieve these objectives. Other models that have been developed, such as incrementalism and pluralism, go more towards understanding the process of decision-making, although a notion of rationality, once again, is assumed to some degree.

c) Incremental model (muddling through)

Incrementalism (also referred to as 'muddling through'[73] or the method of 'successive limited comparisons'[73]) is based on the notion that policy should be

founded on a rational decision. Rationality is linked to political and organisational concerns[101], which can be referred to as "collective rationality" (Gregory, p.229[102]). This suggests that although an organisation might be rational, individuals within it may deviate from this, although the nature of this is not specified. In this model, decisions are made through an iterative process and decision makers perform marginal or incremental comparisons, so that decisions differ only slightly from previous decisions. The reasons for making only marginal changes in decisions might be because of the difficulty in terms of time and money to gather information. "Disjointed incrementalism"[103] is a latter variant of this model, suggesting that decision-making is incremental because it is undertaken by different agencies within an organisation. It is more difficult to see how economic evaluation would influence decision-making where that decision-making is incrementalist in nature.

d) Pluralism

Pluralism suggests that the level of rationality is at the micro or individual level, rather than at the organisational level. Pluralism essentially means that there is more than one decision maker; in fact usually there is a range of different decision makers each competing so that power over decision-making becomes a crucial concept. The appropriate definition of power, however, has caused some debate. Dahl[104] views power as:

A has the power over B to the extent that he can get B to do something that B would not otherwise do.
(Dahl, p.203-204[104])

This focuses on conflicts of interest. However, from this, it is not possible to know how B would have behaved had it not been for A's actions.[105] Instead, Lukes[106] proposed a 'two-dimensional' view of power, noting that:

A also exercises power...by influencing, shaping or determining his very wants.
(Lukes, p.21[106])

This associates the notion of power with authority. It is likely that, as Bachrach and Baratz[107] suggest, understanding power involves examining actual behaviour and the process of decision-making. Bachrach and Baratz[107] suggest that power struggles might be reflected in the extent to which a non-decision occurs:

Demands for change in the existing allocation of benefits and privileges in the community can be suffocated before they are even voiced; or kept covert; or killed before they gain access to the relevant decision-making arena; or, failing all these things, maimed or destroyed in the decision-implementing stage of the policy process.
(Bachrach and Baratz, p.44[107])

Pluralism and "political decision-making" has been comprehensively explained by Allison, writing about the missile crisis in Cuba.[108] The discovery of Soviet nuclear missiles in Cuba posed a challenge to Kennedy (the US president). The task was to persuade Krushchev (Soviet president) to withdraw the missiles, which he eventually succeeded in doing, by imposing a naval blockade. However, there was a considerable amount of bluff on the US side should the Soviets have decided to breech the blockade. Thus the relative power and bargaining abilities determined outcomes,[108] and although Kennedy might have been seen as rational, the way that the process of decision-making occurred was not straight forward.

The concept of power presents a problem for rational choice theory. The latter usually abstracts from the institutional context, and the phenomenon of power, for instance in theory of the markets, is absent.[80] Although new institutional economists have taken more of an interest in the institution, this focus tends to be on the institutional environment (such as the nature of bureaucracy) and the governance (as in transactions costs) rather than on notions of power.[109] Pluralistic decision-making may potentially be influenced by economic evaluation but in such a process it would need a champion whose aim is to ensure rational decision-making. Even with such a champion the different actors with their different incentives may take little notice of the rational solution.

2.2 *Non-rationality: anarchy or garbage can model*

The anarchy or garbage can model illustrates that decision-making does not occur in an ordered manner, but as a complex interaction of four factors or streams of events: problems, solutions, participants, and choice opportunities.[75] They describe this as follows:

An organisation is a collection of choices looking for problems, issues and feelings looking for decision situations in which they might be aired, solutions looking for issues to which they might be the answer, and decision makers looking for work.
(Cohen, March and Olsen, p.2[75])

Problems represent the divergence between an actual and a desired situation. Solutions help to formulate problems, which is contrary to classic rationality, where solutions are only developed in response to problems. Participants are defined as the flow of people involved in decision-making, whose involvement in the decision-making process is restricted by time pressures. Choice opportunities are the occasions when the organisation is expected to make a decision. The garbage can analogy is quite appropriate: people randomly discard rubbish and it is thrown together based on random interactions. In a garbage can, at any one point in time, there might be teabags stuck to crisp wrappers, only because they happened to be thrown together at the same time (*i.e.* by coincidence). Similarly, decision-making might not follow an orderly series of steps. Thus, individuals can be assigned projects because of a low workload, and not necessarily because they are solving a problem and are really needed.[96] The model further suggests that examining consequences in terms of objectives does not necessarily help to understand the decision-making process.[75] Instead decision-making occurs when the four streams of events meet. [75] Hence problem identification and the solution might be unrelated and decisions can be made without solving problems.

The garbage can model can be seen as a challenge to individual and organisational rationality. For instance, it suggests that there can be radical and unexpected changes in policy, unlike the incremental model where current

policy is a version of previous policy. However, a possible weakness of the garbage can model is that it does not take into account attempts to be rational, suggesting little or no role for economic evaluation.

3. Allocative decision-making in the NHS

Based on the detailed and comprehensive review of decision-making so far, attention is now turned to one of the main themes running through this thesis: how are allocative decisions made in the NHS? This section is devoted to exploring allocative decision-making (commonly referred to as rationing[48, 110] or priority setting[32, 111, 112]) in the NHS. Such decisions concern which treatments or services to provide to patients in view of scarcity of resources. There is growing interest in the organisation and delivery of health care, as well as how decisions are made in the NHS, as a result of a perceived increase in the shortfall between expectations and what is available, commonly believed to be caused by an increasingly older population[113] and improvements in medical technology.[114] Types of rationing can be differentiated according to the degree of explicitness, where there is 'implicit' and 'explicit' rationing, although these are a continuum and in practice most health care rationing is a mixture of both.[111] In this section, relevant empirical evidence is drawn upon in relation to the models of decision-making. It appears that whilst implicit rationing has elements of pluralistic bargaining, incrementalism, and non-rationality, explicit rationing is based on classic rationality.

3.1 Implicit rationing: pluralistic bargaining, incrementalism, and non-rationality

Implicit rationing has elements of pluralistic bargaining, incrementalism, and non-rationality. Implicit rationing is "the unacknowledged limitation of care, inevitably occurring where there is no explicit rationing" (Coast *et al*, p.8[111]) particularly when clinicians (hospital doctors or GPs) make decisions for individual patients and are working within fixed budgets.[115] These decisions and the reasonings behind these decisions (such as, for instance, equity, cost, or

health gain) are not clearly expressed however.[111] In the NHS, GPs act as gatekeepers to secondary care, to control patients' access to specialist services. GPs decide which patients are in need of referring, based on some externally undefined criteria (although now the targets dictate a substantial amount of GP referral decisions, and this is also an explicit form of rationing).[111]

Custom and practice and historical allocations (or basing decisions on what has been funded previously)[116, 117] are two major ways in which implicit rationing is undertaken. The former case is the most common form of implicit rationing, where decisions are dependent on clinicians' judgements about the appropriate course of action, based on what the clinician was taught, their interpretation of the evidence, or prevailing practice, although there is no set procedure for rationing.[47] Basing decisions on custom and practice is often value based and can disregard the resource impact of implementing priorities.[112, 118] This, in turn, may lead to inefficient provision of services. Similarly, basing decisions on historical allocations might be inefficient because it is presumed, similar to the incremental model of decision-making, that what has been done previously is optimal and can be revised slightly.

With the existence of implicit rationing in the NHS and as a result of clinicians' autonomy and power in individual patient decision-making, decisions could also be seen as being made within a pluralistic framework, involving bargaining between clinicians and meso decision makers (who are also powerful because of their management role, but do not necessarily have patient contact).[32, 119, 120] However, clinician autonomy, as under GP fundholding for instance[121], has been curtailed in the movement towards 'clinical governance' policy since the 1980's[122], away from professional self-regulation and in favour of tighter monitoring and control of clinicians (particularly hospital doctors).[123, 124] Little is known about how this has affected micro level decision-making.

On the other hand, there is also evidence to suggest 'irrationality' in decision-making by clinicians.[54, 125, 126] Jones *et al*[119] showed how GPs often expressed

irrationality in much of their decision-making. They were frustrated by attempts by them, or by the Government, to encourage them to be more rational when other decisions were clearly not based on rational criteria. Some GPs felt that much of Government policy was irrational and were therefore dissociated to ration in their own clinical practice. In some cases, they were resorting to a solution without solving the problem of how to deliver the national directives and provide the best local care for their patients.

3.2 Explicit rationing: classic rationality

Explicit rationing occurs when decisions about resource allocation are made according to *specific criteria,* which have been made clear or explicit.[111] Explicit priority setting processes have arisen in the UK, US, New Zealand, the Netherlands, and Sweden, as a result of resource constraints and rising patient expectations.[94]

Explicit rationing can involve technical methods, such as cost-effectiveness analysis and/or political methods[111], which are usually less explicit. Political methods include:

- Long waiting lists, to cope with the disparity between demand and supply;[127]
- A ranking system, whereby a scoring index is developed in order to prioritise services;[128]
- Limiting treatment, with regard to specific disease areas, populations, localities, or groups,[129] such as white-collar workers or those within a specific age range (commonly referred to as age based rationing[130]).

Most explicit approaches attempt to determine relative 'need', by measuring the amount of ill health categorised by disease, and allocating priorities according to the size of the need.[131] Need is, however, likely to be only one aspect of decision-making. For instance, apart from the need for the intervention, criteria among clinicians performing cardiothoracic surgery in Sweden included

evidence, risk assessment, benefit to patients, quality of life or satisfaction of patients, and severity of illness.[132]

Some researchers have claimed that decision-making based on need assessment is a "systematic approach to ensuring that the health service uses its resources to improve the health of the population in the most efficient way" (Wright *et al*, p.1310[133]). However, the approach can only inform decision makers as to whether one problem is more serious than another - it does not inform resource allocation decisions by maximising the health gain of the community,[134] and therefore has little appeal among health economists. Donaldson[131] firmly states that the need approach ignores the fact that a) "it is not the size of the disease or illness that counts but what should be done about it in terms of the *effectiveness* of interventions" (Donaldson, p.81,[131] emphasis added) and b) the importance of assessing *costs* resulting from health care interventions. In recent years, priority setting forums for (such as those in Oxfordshire and Berkshire health regions) have tried to make decision-making more explicit using criteria, some of which might be related to costs and effectiveness, so that decisions are not made exclusively on the basis of need.[135]

In practice, however, explicit rationing is not a wholly comfortable notion among health care decision makers[136] and it might be easier to use implicit rationing rather than to explicitly make difficult choices.[129] There have been examples where implicit decisions have been made explicit and these have led to negative public attention towards health care commissioners. For instance, one locally contested decision involved a four-year-old child with a malignant brain tumour.[30] Despite specialist opinion advising that there was no curative treatment, the parents of the child referred themselves to a specialist in the US who claimed that he could operate with a 20% chance of success. The local Member of Parliament (MP) helped the family to visit the US and requested NHS funding but the local commissioners refused to pay. The local public support paid for the treatment and the local commissioners were severely criticised by the media for not helping the child, who died four months after

returning to the UK. The case shows how decision-making is complex because of the emotive nature of the decisions and the media's portrayal of ('unjust') decisions made on the basis of money.

There is a tendency among health authorities to want to "avoid blame"[114] by not making rationing decisions. Using semi-structured interviews with members of health care professionals, Coast found there was a desire to avoid disutility associated with denying care.[120] Local decision makers are likely to face obstacles in making rationing decisions for the community because of vested interests from politicians, clinicians, Trusts, and pressure groups. Coast found that there is likely to be a 'dilution' and 'reinterpretation' of decisions as choices made locally are translated into practice at lower levels within the health care system. In particular, clinicians found it difficult to try and do the best for the patient and avoid denying care. This might explain why local decision makers often look to the Government to make allocative decisions.[132, 137]

There is also some evidence to suggest that managers themselves might not think they are well placed to perform explicit rationing. The small amount of literature which exists on this topic is drawn mainly from the UK, Canada, and Australia. The literature from Canada suggests that, in practice, health authorities find it difficult to balance competing pressures from the provincial government, their providers, and their citizens, meaning that accountability might be fragmented.[138] Further evidence from Canada suggests that decision makers are likely to find the priority setting process lacking in transparency, some referring to it as a "black box", with a lack of clarity about how priority setting decisions are made.[116] Further light is shed by work conducted by Miller and Vale[139] in the UK, showing how priority setting is conducted within a reactive environment (somewhat similar to the Canadian experience of reacting to providers, the Government, and to the media), leaving little freedom for proactively developing strategy. The economics literature has, on the whole, not considered where decisions are influenced by people's behaviour or emotion, although there are some exceptions.[120] The literature has also not fully

explored the incentives of decision makers in priority setting. Whilst decision makers have claimed, for instance, to have an interest in health care and a desire to be part of decision-making,[140] it is not clear how personal motivations (for instance financial incentives) might have a role to play. Neglect of these important issues has largely arisen because the methods used (such as postal surveys[140], structured interviews[116] or semi-structured interviews[139]) have not been sufficiently sensitive to capture 'real life' decision-making. It is likely that, as Miller and Vale[139] point out, future work on priority setting should be in areas of behavioural sciences.

There are also practical barriers to explicit, evidence-based priority setting in practice, including difficulty in accessing information, lack of interpretation skills, and lack of timely or 'good' information.[112] It is likely that facilitators to using economics will include the creation of incentive systems to assist decision makers in moving towards informed, explicit priority setting, and involving clinicians in the process in order to create accountability and acceptability of the policy decisions.[112]

Whether health care systems should operate on an implicit or explicit basis has caused contention among academics. There are those who have argued that implicit rationing is associated with unfairness and inequity,[62, 141] and, on the other hand, those who maintain the potential disutility from explicit rationing.[136, 142, 143]

4. Research utilisation

The penultimate section of this chapter explores use of research evidence in decision-making. This is an important issue because it can reflect the degree of explicitness of decision-making and the way in which decisions are assumed to be made. Use of research evidence is also a particularly important topic in health care since decisions are essentially made about other people's lives, and decisions therefore, one might assume, should be supported by such evidence. This section draws upon leading review papers on the use of research evidence,

particularly in relation to health care. The section discusses the theory surrounding research, the ways in which research is used in health care in practice, and the general mechanisms, which have been proposed to facilitate greater use.

4.1 Theory of research use

The UK Government Cabinet Office describes evidence as:

Expert knowledge; published research; existing statistics; stakeholder consultations; previous policy evaluations; the Internet; outcomes from consultations; costing of policy options; outputs from economic and statistical modelling.
(The UK Government Cabinet Office, in Nutley, p.3[144])

Evidence in health care relates to published research, clinical experience, patient experience, and information about the local context.[145] Evidence therefore includes informal knowledge gained, as well as knowledge gained from published research or reports. However, there are likely to be different levels of importance attached to diverse forms of evidence in health care. Among academics, there appears to be a hierarchy of evidence, which places RCTs at the apex, observational studies below, and professional opinions much lower down.[144] Explicit ranking of types of evidence in health care is likely to have arisen because it is generally accepted that biased conclusions can be drawn from less methodologically rigorous studies. However, among doctors, it is likely that informed knowledge, including professional opinion, will be very important.[146]

There is a spectrum of research use, generally ranging from direct or instrumental use (which results in changes in practice or policy making) to non-instrumental, conceptual, or indirect use (which brings about changes in levels of understanding, knowledge and attitude).[147] Various examples are shown in Table 1.5.

Table 1.5: examples of 'use' of research

Spectrum of use
o Changes in access to research
o Changes in the extent to which research is considered, referred or read
o Citation in documents
o Changes in knowledge and understanding
o Changes in attitudes and beliefs
o Changes in behaviour

(Walter *et al*, p.11[147])

Weiss,[148, 149] whose work has informed much of the current thinking on research use in policy-making,[150] proposes that the term "research utilisation" has evoked different meanings. Each differs in terms of how research is used and how it enters into the decision-making process. Weiss[148] defined two broad models of research utilisation: linear and non-linear. Linear models assume research is used in a very ordered and sequential way. Such models of research utilisation in decision-making suppose a rational decision-making model. The two linear models of research utilisation are the "Knowledge-Driven Model"[148] and the "Problem-Solving Model".[148] These models are discussed in turn, followed by a discussion of the (four) non-linear models, which can be seen as being related to a more incrementalist view of decision-making, where decision-making involves a series of steps over a long period.

The "Knowledge-Driven Model"[148] assumes that the following sequence of events occurs: basic research, applied research, development, and application. Basic research is thought to create an opportunity for use in public policy; applied research is then conducted; appropriate technologies are developed to implement the findings of the research; leading to application of the research. In this sense, research has created the opportunity for application. Examples of the knowledge-driven model of research utilisation generally come from the physical sciences, whereas social science provides few examples. There are several reasons why this would be the case: social science research is often not

so compelling as to be automatically used; such research does not usually support specific technologies, as in the physical sciences; and research is less likely to be used unless it has received consensus since decision-making tends to occur in a political arena.[149]

The "Problem-Solving Model"[148] proposes that a problem exists and a decision has to be made. Hence, unlike the previous model, there is a specific quest for information to resolve a problem or reach a decision. Generally, research can enter the policy-making arena in two ways: either existing before the policy problem or commissioned subsequently to fill a knowledge gap. The Expected Value of Perfect Information (EVPI) model used by economists is an example of how decision-making is assumed to be rational. Here the objective is to decide on the basis of existing evidence, about costs and benefits, whether more research should be conducted.[151] It is assumed that obtaining further information will enable decisions to be made with greater certainty than is currently possible and from these models it is possible to determine when collecting further data is worthwhile and when it is not. The problem-solving model assumes decision makers have a clear idea of their goals and that they have already identified informational needs. It is also assumed that: research will have a direct and immediate applicability and will be used for decision-making; there is a well defined decision; decision makers are responsible and able to make the decision; there is a decision whose resolution depends on information; information needs have been identified; research matches the circumstances in which the decision will be made; and research findings are unambiguous and comprehensive. These assumptions point to research use within classic rationality.

Weiss believed that although linear models were an important reference point, they could not accurately reflect the use of social science research in public policy making and non-linear models were more applicable.[149] Weiss suggests that the conceptual (indirect or non-instrumental) use of research findings would be more common in social sciences:

Officials apparently use social science as a general guide to reinforce their sense of the world and make sense of that part of it that is still unmapped or confusing. A bit of legitimating here, some ammunition for the political wars there, but a hearty dose of conceptual use to clarify the complexities of life.
(Weiss, p.17[149])

There are four different models within the broader non-linear models. Firstly, research can be used as part of a wider influence, so that it is one of many competing factors. The "Interactive Model"[148] describes a situation where research enters the decision-making arena as a search for knowledge by decision makers. Social scientists are one group among many, competing for influence on decision-making. They will rarely have research that bears directly on the policy issue however, and other factors, such as political issues, will be important.

Secondly, research evidence can also be used to legitimise a particular action. The "Political Model"[148] suggests decision makers are unlikely to be receptive to research, because of other conflicting interests. To support a particular case, however, decision makers will use research as "ammunition". Indeed, political economy adherents would view Evidence Based Medicine (EBM)[v] as a resource that medics use to buttress their authority.[153] Alternatively, EBM might enter into the political process (for example through clinical guidelines) as a way in which the national level restricts clinical authority.[153] Thirdly, the "Tactical Model"[148] suggests decision makers use research as a tactic, for example in delaying action or decisions they are not particularly keen to make. Finally, the "Enlightenment Model"[148] suggests that through illumination, research can generally penetrate into decision makers' way of thinking. Weiss, however, felt it was important to recognise there are obvious deficiencies in the level of 'enlightenment' achieved, in that much of the research that gains its way into people's minds has been oversimplified or is wrong.

[v] EBM is an attempt to introduce more objective, quantifiable estimates of clinical variables to medical practice.[152] It therefore aims to ensure that scientific research, as opposed to individual patient decision-making, is the fundamental ground of clinical decision-making.[153]

Although research might be used in various ways, as the models by Weiss suggest, it is likely that those based on classic rationality offer limited insight into how social science research is actually used, particularly at local rather than national levels. In health care, it seems that research use is influenced by many factors that the rational model assumes to be exogenous, including the content, actors, process, and context of decision-making.[154, 155] Consequently, it is far more likely that alternative models, which pay attention to how decisions are made, are of greater relevance in understanding how research is used. For instance, it would be difficult to understand how rational use of research could apply to allocative health care decision-making concerning unexpected decisions needing to be made for the treatment of individuals. Here, it might not be possible for local health authorities to predict their use of research evidence. Instead, it might be thought that local health authorities would be more likely to use clinical research evidence as "ammunition" (as in the political model) to support their case for not funding treatment for instance.

4.2 Practice of research use

Findings from systematic reviews suggest that the direct application of research is a relatively uncommon phenomenon in policy making.[144, 147] Examples from health care reiterate this, suggesting a lack of direct utilisation.[156,157] The barriers identified to using research directly are shown in Table 1.6:

Table 1.6: barriers to research utilisation

Barriers to research use
o Lack of time of policy makers
o Low priority of research in relation to internal and external pressures
o Poor communication of research within organisations
o Perceptions of research - for example, internally conducted research is more likely to be seen as relevant and hence considered
o Research is not timely or relevant to users needs
o Research is less likely to be used where findings are controversial
o Other sources of information may be valued more highly
o Individual resistance to research, especially when a threat to "craft" skills and experience
o Failure to value research at the organisational level or a hostile organisational culture
o Conflicting research outcomes

(Adapted from Walter *et al*, p.27-28[147])

In the field of health care, research is likely to be only one of several sources of information decision makers use when making decisions.[150, 154, 158, 159] For instance, clinicians have a substantial degree of autonomy in their individual decision-making and it is thought that they might be more likely to base decisions on personal experience rather than research evidence.[160] A recent study found this to be the case,[161] where factors in decision-making for Drugs and Therapeutics Committees (DTCs) of two general hospitals in the UK included clinical trial data, cost, pre-existing prescribing patterns of drugs, pharmaceutical company activities, decisions of other DTCs, and "clinician excitement" (or the level of interest in the intervention expressed by the clinician). The authors advocate recognition of the difference between the "formal rationality of science and the local rationality of health care provision" (Jenkings and Barber, p.10[161]), highlighting limitations of the assumptions of the classic rationality.

Other studies of research use in health care have similarly found the direct use of research to be limited in practice. In a study of the use of federal health evaluation research, Patton *et al* perceived that research was used, but not in the unambiguous way social scientists often assume.[162] They conclude that definition of "use" has often been too narrow and has failed to give attention to the nature of the decision-making process. Research was found to be used to support opinions or intentions of decision makers, as would seem to be similar to the political model of research use, but also fed slowly into the process over time (perhaps akin to the enlightenment model of research utilisation). The main barriers to research use were not related to any the authors had assumed (such as methodological quality and timeliness of studies), but were associated with political factors (in that decision-making is a political process depending on whose priorities are being reviewed) and a "personal factor" including the leadership, interest, and enthusiasm of decision makers.

In relation to factors that facilitate or impede use of EBM in the NHS, Elliott and Popay[150] suggest that the contribution of research to policy making is more similar to the interactive model than the problem-solving model. Through in depth interviews with twenty-eight decision makers, it was found that the direct influence of research evidence on decision-making was hindered by constraints in the amount of money available, as well as decision makers' own experience. In addition, in health care it has been claimed that there is not enough time to read research[163], perhaps because of a heavy workload (particularly among GPs[164]) and that research is not conducive to understanding, because of the complex methods and jargon used.[165] It is therefore unsurprising to discover that doctors tend to read editorials or commentaries, which are easier to follow, than original papers.[166]

Barriers from the researcher's side (or those producing the research) might also be relevant. Researchers are likely to be concerned with other factors aside from the usefulness of their research, including enhancing their status and obtaining

financial or non-financial rewards.[149, 162] As O'Donnell (a medic) succinctly put it:

Scientific papers are not written to disseminate information...but to be published. Authors are eager to get their names in print not because they are bursting to tell us something but for more solemn reasons. Another paper means another line on a curriculum vitae, another step towards a job or a research grant.
(O'Donnell[167])

This factor does not appear to have been extensively researched, or found, in the literature however.

4.3 Increasing the impact of research

Various measures have been proposed to ensure that research enters into the decision-making process (Table 1.7). Here, it is generally assumed that passive dissemination of research is of limited value.

Table 1.7: practices to enhance impact of research

Practices to enhance impact of research
o Active dissemination of research
o Educational strategies and those which allow interaction with colleagues and experts
o Supportive opinion leaders
o Developing closer links between researchers and practitioners, for example through partnerships
o Support for practitioners to "try out" research findings and conduct their own research
o Reminders
o Adequately resourced facilitative strategies
o Multifaceted interventions (*i.e.* using more than one type of intervention)

(Walter *et al*, p.29[147])

The suggestion for interfaces between researchers and policy makers,[155, 156, 168] point to an interactive model of research utilisation. Examples of interfaces include the creation of committees of decision makers and researchers.[156]

However, it is also recognised that there need to be incentives for researchers to produce utilisable research[156] and research that is of good quality.[144, 169, 251] In this respect, there have been various initiatives over the past few years to increase the quality of research in health care. For instance, the Cochrane Collaboration[170] produces and disseminates systematic reviews for selected health care interventions. Such initiatives assume that research is also more likely to be more influential if it is topical and/or timely.[157, 169] Finally, there is some concern about conducting research that answers the questions that decision makers are interested in.[171] Here, an understanding of the decision-making context (including the doctor-patient relationship) is vital in improving the targeting of research.[172]

5. Conclusion

Health care decision-making is complex because of the organisation of health care and the behaviour of decision makers within the organisation. There appear to be three models of organisation in health care (the market, command and control, and network), although it is difficult to establish from the literature which model is most pertinent to the NHS currently. The simultaneous use of different organisational forms may well have created perverse incentives, where local decision makers are torn between self-interest (as assumed in the command and control model) and societal concerns (assumed in the network model).[9, 173] Understanding the behaviour of decision makers within the NHS is also complex and there is little clarity about the process of making allocative decisions at the meso level, either in the academic literature, or, it appears, among those involved in the process. Academics have applied a variety of theoretical models, such as the political model and garbage can model, but the small amount of empirical work suggests that there is confusion as to how rationing is achieved in practice, or whether it is possible to comprehend this complex topic at all. In particular, there appear to be fundamental questions left unanswered. For instance, although there might be political decision-making in the NHS, based on power struggles, how does this relate to the disparate and powerful groups in the NHS alongside the control from the Government? In

addition, does any form of extended classic rationality apply to health care decision-making, such as game playing or process utility? Furthermore, links between organisational change and the decision-making that takes place in the NHS have seldom been made.

It might be reasonable to suspect that economists have a particular view of health care decision-making. They tend to assume: explicit rationing is feasible; there is a classic rationality among decision makers; as well as a rational model of research utilisation. In practice, the empirical evidence for the NHS suggests that implicit rationing, based on other forms of rationality and non-rationality, rather than classic rationality, is more likely. It appears to be also rarely the case that research evidence will be used directly in health care, because of the variety of actors involved and the politics associated with health care decision-making. Thus, health economists are unlikely to be aware of how decisions might be made in the NHS, the priority setting process that takes place, and the usefulness of the work typically produced. It may well be assumed that economic evaluation is directly relevant and applicable to decision makers. Further research is clearly needed to find out whether these assumptions hold in practice and the implications this has for the discipline of health economics.

It appears, therefore, that there may be some diversity between the context in which decision-making takes place and the context assumed by economists. The context in which decision-making takes place appears ambiguous in both organisational form and the nature of decision-making. Despite this, economists have developed decision-making tools based on an assumed rationality. The nature of these models and the evidence about their value is explored in chapter 2.

Chapter 2: Use of economic evaluation in health care decision-making

Economic evaluation is not being used to its full potential. In short, economic evaluation is sometimes used, is often not used, probably should more often be used, and ways can be found to increase its use. However, I might be kidding myself!
(Drummond, p.9[174])

This point of view, from a UK health economist, highlights the concern about the extent to which economic evaluation is used in practice. The purpose of this chapter is to evaluate the literature on the contribution of economic evaluation to local decision-making. This chapter first provides a brief outline of economic evaluation, so as to put the use of economic evaluation into an appropriate context. The chapter then evaluates the topic of this chapter, using data drawn from a systematic review conducted as part of the thesis. Included sections are: the use of economic evaluation; barriers to use; and ways in which greater use might be facilitated. The penultimate section explores the methods that have been employed in the empirical studies of use of economic evaluation. The chapter concludes by highlighting the need for further work using more in-depth methods that avoid the potential for respondents to exaggerate their use of economic evaluation.

1. Economic evaluation

Economic evaluation has been defined as "the comparative analysis of alternative courses of action in terms of their costs and consequences" (Drummond *et al*, p.9[175]), hence involving two parameters –costs and outcomes. Economic evaluations are not only concerned with costs, since an intervention or programme might be cheap but represent poor value for money.[176] The concept of opportunity cost is fundamental to health economics and therefore to economic evaluation.[177] Opportunity cost is based upon the idea of scarcity of resources, so that the opportunity cost of undertaking an activity is the benefits that are forgone by not allocating resources to the next best activity.[177] Opportunity cost will depend on the viewpoint employed (such as patient or

societal).[178] So, for instance, the opportunity cost of expanding a breast clinic might be the forgone benefits of developing the next best alternative, such as expanding an oncology clinic or buying a new piece of equipment. However, if a wider perspective is taken than the hospital, such as the entire local health care system, the opportunity costs might be different, such as a reduction in community care as a result of investing in the hospital.

Economics, and economic evaluation, are primarily concerned with efficiency, which involves obtaining the maximum benefits from a given amount of resources.[178] There are two types of efficiency - technical and allocative efficiency.[179] Technical efficiency involves achieving a given objective with the least possible expenditure. For example, the most technically efficient way of achieving the objective to reduce waiting times in hospital will be the lowest cost option, other things being equal.[176] Allocative efficiency involves producing exactly the quantity and type of health care that society wants. It differs from technical efficiency because a value judgement must be made as to which objective is worth pursuing, rather than deciding which programme will meet the objective.[176] For example, it might be necessary to assess whether it is worthwhile expanding a clinic for oncology patients or employing additional clinical staff to reduce A&E waiting times, where both of these programmes have differing objectives.

There are generally three specific methods of economic evaluation: Cost Benefit Analysis (CBA), Cost Effectiveness Analysis (CEA), and Cost Utility Analysis (CUA). It could be argued that CBA deals with allocative efficiency, since comparison of costs and benefits are made across programmes serving different patient groups (for example a CBA can be conducted for orthopaedic care versus cancer care).[180] A monetary value can be placed on an intervention by asking people what is the maximum amount they would be willing to pay for it (or, alternatively, how much they would be willing to pay to avoid the effects of, for example, illness).[181] The Net Social Benefit (NSB) of a treatment can be calculated using the following formula:[181]

$NSB_i = W_i - C_i - C_s$

Where W is society's willingness to pay for the benefits offered by the intervention, C_i is the cost to the health service of the treatment, and C_s are the societal costs (outside the health care system).[181] It is suggested that CBA using monetary valuation of outcomes facilitates the comparison of disparate programmes[181] (for instance comparing health programmes and educational programmes for schools) and it is also clear what amount of money must be given up in order to fund any new intervention. In addition, willingness to pay has been suggested as one method for detecting process utility in health care, so that utility is not only derived from health gain but also from the value in using health care,[182] although evidence on the existence of process utility is mixed.

However, although there are three types of classic economic evaluation, contention exists among health economists as to the different perspectives undertaken and specifically whether economic evaluation should be conducted from a welfarist or non-welfarist perspective [183] (the latter is also termed 'extra welfarist'[183] or 'decision maker approach'[184]). Welfare economics suggests that individuals maximise utility and that the overall welfare of society is a function of individual utilities.[175, 179] Paretian welfare economics suggests that an optimal state is reached when no-one can be made better off without making someone else worse off.[183] It is difficult to imagine situations where this would occur, so the compensation principle was developed, whereby potential losers can be offered compensation by potential gainers (although this does not require that compensation is actually paid, but that it could be, hypothetically, paid).[185] The compensation principle allows the number of programmes that can be ranked to increase considerably in comparison to what is achievable using the Pareto test.

However, there is concern among some economists that it is not possible to use CBA in health care decision-making because of the reliance on valuing outcomes in monetary terms.[175] For this reason, the non-welfarist approach

allows for measuring consequences of alternative policies in a way that is not necessarily in line with the way individuals would value them. Non-welfarist approaches typically measure health gains,[183] with the aim of maximising health in a community from a given budget.[184] Because consequences of alternative polices are not necessarily valued in the way individuals would chose to value them, some have argued that CEA and CUA are conducted from a non-welfarist perspective.[186] In fact, the welfarist and non-welfarist positions have been much debated in the literature, with some health economists feeling that non-welfarist approaches, where health (as opposed to utility) is the final outcome of concern (taking into account other non-good characteristics such as freedom from pain and mobility) is a more accurate representation of well-being.[187] Welfarist economists are likely to be reluctant to adopt this perspective, feeling that it is not possible to apply valuations uniformly across people, regardless of their individual valuations, without violating the Pareto principle.[180]

In CEA, the focus is on a single outcome measure,[175] such as reduction in blood pressure[181] or life-years saved,[175] hence only interventions which have the same outcome measures can be compared. The main measure used in CEA is the Incremental Cost Effectiveness Ratio (ICER) which gives "the incremental price of obtaining a unit health effect" (Gold *et al*, p.27[179]). For two treatments, current treatment A and new treatment B, the ICER is defined as[181]:

$$ICER = (C_B - C_A) / (E_B - E_A)$$

Where C represents costs and E represents outcomes for the interventions.[181] Clearly, there is no need to calculate this ratio when an intervention is both more effective and less costly (and here the alternative is said to "dominate" current practice).[179] It is assumed that programmes are divisible with constant returns to scale.[188] Divisible means that they can be partially implemented and constant returns to scale means costs and effects are proportional to the scale of implementation. However there are specific problems introduced by indivisibilities, since the optimal combination of A or B cannot be facilitated

without integer programming. In addition, increasing returns to scale might mean that a mixture of A and B is better than full implementation of either.

CUA is a variant of CEA. As with CEA, comparisons cannot be made between programmes in different sectors of the economy (for instance, CUA cannot advise whether to open a new hospital or build a new road, since outcomes will be different). Outcomes are combined into a single index combining length of life and quality of life.[181] Preferences of society are taken into account to some extent (since valuations are population based and applied across all affected people regardless of their individual valuations - hence individual valuations might be different from societal valuations).[175] The most commonly used measure is the Quality Adjusted Life Year (QALY). QALYs are a measure of quality of life and are anchored on a scale of 0 to +1 where 0 is equivalent to death and +1 is the best or optimal health state imaginable (although negative states are permitted). QALY weights typically measure various aspects of morbidity assessed by the patient or their carer. For instance, the EQ5D or EuroQol assesses Quality of Life (QOL) according to five criteria: mobility; self-care; usual activities; pain/discomfort; and anxiety/depression.[189] Each of these dimensions has three levels, ranging from no problems to extreme difficulty for each dimension. Composite health states are generated to have a five-digit code number relating to the relevant level of each dimension.[vi] These weights are multiplied by the expected duration of treatment (often life expectancy) in a particular health state to obtain life years that incorporate an element of morbidity.[175] A cost per QALY gained estimate can then be used in an assessment of efficiency. The principle advantage of QALYs over health effects is that for the latter comparison cannot be made between ICERs from different programmes, but with QALYs comparison can be made between cost per QALYs of different programmes. Disability Adjusted Life Years (DALYS) are an alternative measure where, apart from combining information about

[vi] For instance, 11223 would mean no problems with walking about, no problems with self care, some problems with performing usual activities, moderate pain or distress, and extremely anxious and depressed.

mortality and morbidity, age-weighting and or disability weighting can be used.[190]

QALYs, however, have not been without criticism. Four main criticisms are as follows. Firstly, the assumption of constant proportional trade-off between length of life and health status (meaning that the individual is prepared to sacrifice some constant proportion of their remaining years of life in order to achieve a given improvement in health status) might not hold.[191] Hence, an individual who regards 12 years in excellent health as equivalent to 15 in their current state of health, might not regard 4 years of excellent health as equivalent to 5 in their current health state.[191] Secondly, it is assumed that the individual has a constant proportional risk attitude, with respect to treatment length for example, which might not be the case, since an individual might exhibit both risk aversion and risk seeking behaviour in different time periods.[191] Thirdly, it is assumed that the value assigned to each state is independent of the time spent in the health state and experience of other proceeding health states, which might not hold, particularly for chronic illnesses. Finally, there are issues of equity, which QALYs have not taken into account. QALY maximisation might discriminate against the elderly and the infirm, or those with a lower than average capacity to benefit.[192] Empirical evidence has also shown that people have revealed a tendency to want to sacrifice quality of life gains in order to prioritise the severely ill (the rule of rescue principle).[193] Rawles[194] has claimed that assessing outcome on the basis of QALYs is inequitable. Although Mooney accepts that maximising QALYs will not necessarily embrace equity, he feels, however, that this is not the objective they seek and that other methods of prioritising, as suggested by Rawles, such as 'shroud waving' (or publicly announcing that unless resources are increased patients will die) are unlikely to be equitable anyway.[195]

It is likely that further research is needed to understand people's preferences for rationing on the basis of QALYs, particularly to find out the significance of key factors (such as age and severity of illness).[193] Empirical studies assessing

whether maximisation of QALYs hold have also involved decisions surrounding organ transplantation[196, 197] (where it is likely that people are more readily accepting of rationing), although empirical studies are also needed regarding rationing for other more commonly delivered treatments or services that are not life threatening.

There are two approaches, the (QALY) league table approach and the threshold approach, which can be used to determine whether an intervention is relatively worthwhile compared to alternative allocations of resources.[198] A league table is a ranked list of all non-dominated programmes in order of increasing ICER.[199] The objective is to implement all programmes, starting from the top, until the budget is exhausted.[199] However, there are various problems with using league tables in practice. Generally studies that have computed the ratios have used different methods and assumptions (such as choice of comparator, discount rate, and time horizon), rendering comparison difficult.[200] In addition, the league table approach assumes perfect divisibility and constant returns to scale, which may not, in practice, hold. At the margin, it may be beneficial, in terms of QALYs gained, to provide a linear combination of programmes, rather than one programme.[201] The use of league tables has therefore been cautioned.[202, 203]

One of the earliest and only examples of explicit priority setting using QALY league tables was in the state of Oregon (US), which drew up a list of priorities for Medicaid and excluded certain categories of treatments from funding.[204] However, as Oregon discovered, using economic techniques to compare costs and benefits was not sufficiently reliable due to the incompatibility of efficiency and equity and Oregon did not use them in practice (although there were other problems such as poor data).[204] Indeed, QALY league tables, as with QALYs, take no account of equity (except that a 'QALY is a QALY is a QALY', no matter who receives it).[177] There is no concern about who receives the gains from society by distributing health care according to a league table, so that the benefits from health care can be obtained by a few, or the very wealthy, as long as this is efficient.

As an alternative to league tables, thresholds (or benchmarks) can be used to appraise individual programmes against a pre-determined cost-effectiveness value.[198, 199] Thresholds are essentially the same as league tables, except that there is a cut off point, where programmes with values less than the threshold are implemented and programmes with values exceeding the threshold are not implemented. One way to look at the threshold rule is to calculate a net benefit by using the estimate of the cost-effectiveness threshold as an 'exchange rate' to convert costs (or benefits) to effectiveness (or cost) units.[205] This net benefit of a programme (N_i) is defined as:[199]

$$N_i \equiv \lambda * E_i - C_i$$

Where λ is an externally set threshold, C represents costs, and E represents outcomes for the interventions. The incremental net benefit of the programme compared to the alternative (N_1) is:[199]

$$\Delta N_i \equiv N_i - N_1$$

The threshold rule is the same as selecting the intervention with the greatest (non-negative) incremental net benefit.[199] In the UK, NICE uses an implicit threshold of £20,000 to £30,000 per QALY[206] (although the existence of a threshold has been firmly refuted by the chair and previous vice chairman of NICE[35]) and in the US it has been claimed to rest at $50,000.[207]

Only if the threshold is well calibrated and the programmes are divisible with constant returns to scale will the threshold rule improve efficiency.[199] When any one of these conditions is not met, the rule could reduce efficiency, by sacrificing more efficient and expandable programmes.[199, 201] Indeed, the threshold approach fails to take into account where the additional resources are taken from to fund the new intervention, and thus the opportunity costs of removing resources from other uses.[201]

A modification of the threshold rule is Cost-Effectiveness Acceptability Curves (CEACs). These do not rely on whether the results of a study fall below a threshold, but, instead, examine the *probability* that a particular study falls below or above a threshold, given the inherent uncertainty surrounding treatment outcomes or costs.[208] The objective is to provide a graphical representation of the probability that, over a range of λ's, an intervention is optimal. Fenwick *et al*[209] propose using a cost-effectiveness frontier which can provide information concerning the uncertainty associated with the a decision. However, neither the league table approach, the threshold approach or CEACs escape the problems mentioned previously with QALYs.

To summarise, although all fit within a broad notion of classic rationality economic evaluation can take a number of forms and have different theoretical bases. Perhaps the greatest contention among health economists is whether economic evaluation should be conducted from a welfarist or non-welfarist perspective. For instance, under the non-welfarist approach, if a programme is accepted, its ICER is the minimum value placed on a QALY by decision makers, given a fixed budget. The question arises as to whether this valuation differs from society's willingness to pay to gain a QALY? In addition, it is not apparent how the ICER relates to different types of efficiency since it only deals with how efficient it is to pursue the programme of interest, and not whether any resources will need to be taken from elsewhere to fund the programme (which essentially deals with issues of allocative, rather than technical, efficiency). Apart from challenges associated with the perspective pursued in economic evaluation, there are also practical and methodological difficulties associated with all forms of economic evaluation. Despite such problems, the numbers of economic evaluations has increased rapidly in recent years.

2. Use of economic evaluation

Given the quantity of resources devoted to the conduct of economic evaluation it is important to assess what the evidence is for its use in decision-making. To

this end, this thesis presents a systematic review of current evidence for use of economic evaluation. The methods of the systematic review are presented, before moving to examine the findings in terms of use of economic evaluation at national and local levels.

2.1 Methods of review

A systematic literature review was conducted to locate studies about the use of economic evaluation in health care decision-making. A range of databases was searched and specific criteria were used to select the most relevant studies. The search strategy used for the review is presented in Table 2.1. Three steps were undertaken:

Table 2.1: search strategy for systematic review

Firstly, MEDLINE and EMBASE databases were search (commencing either in the year 1993 or 1980, to present). The following search terms were used:

1. Health adj1 research.mp
2. (Economic adj1 (evaluation$ or efficiency or appraisal$ or evidence)).tw
3. Cost effectiveness/
4. Cost utility/
5. Cost benefit/
6. Cost minimisation/
7. Health economics
8. Pharmacoeconomics
9. Health policy.tw
10. Health policy (MeSH)
11. Decision$.tw
12. Policy making.tw
13. *Decision making/
14. *Policy making/
15. (Use or utilization or utilisation or implementation).tw
16. Or/1-8
17. Or/9-15
18. 16 and 17

In addition, Web of Science (Wos) and EconLit were also searched, using terms such as 'use of health economics', 'use of economic evaluation', 'priority setting', and 'decision-making'. Several journals (Social Science and Medicine, Health Economics, and British Medical Journal) were also hand searched from the period 1992 to 2005. Aside from this process of collecting published material, grey (non-published work) literature was obtained from HESG conferences, databases, and personal communication.

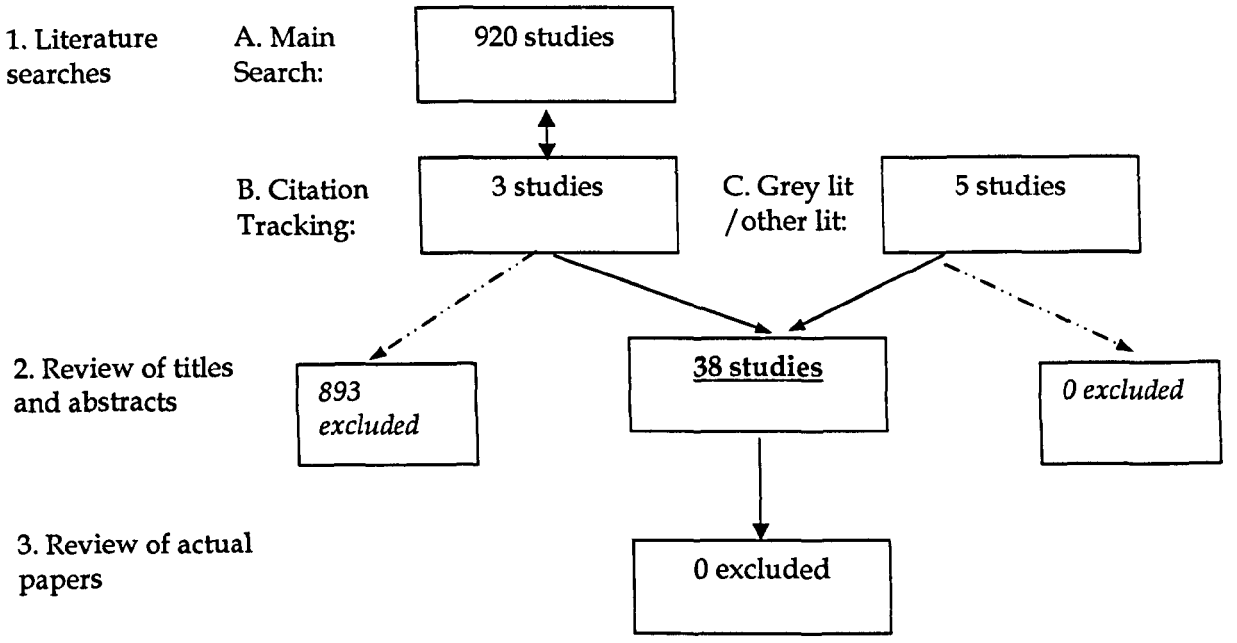
Secondly, articles in MEDLINE (n=923) were screened based on their title and abstract and only studies whose title indicated a major focus on the topic were retained (n=30). EMBASE, WoS, and EconLit did not identify additional empirical work that was used in the review, nor did hand searching of journals identify any additional work. Additional papers were identified from HESG conferences (4), references cited within already obtained studies (3), and personal communication (1).

Thirdly, all remaining studies were categorised according to whether they were empirical or review studies and whether there were policy or practice implications.

Data from selected empirical papers were extracted in a systematic way: data were recorded about the author, year of the study, sample, methods and size of sample, study focus, and main findings.

The process involved in obtaining papers is shown clearly in Figure 2.1.

Figure 2.1: schematic overview of results of literature search



The purpose of the review was to amalgamate all the available empirical work on this topic and to explore the overall findings. Studies were not excluded on the basis of their quality. Examining the quality and methodology of the studies was an important element of the literature review (see section 2.3c), hence excluding studies at this point would not have been appropriate. Studies were only excluded if they were not related to the topic of interest.

2.2 *The macro level*

At the macro level, the strongest evidence of the usefulness of economic evaluation is that of revealed preference.[174] There has been positive evidence of the utilisation of economic evaluation in national health care decision-making, particularly over the past few years, in countries such as the Australia, Canada, and the UK.[210] This has emphasised the increasing importance attached to economic evaluation over time. Requirements for economic evaluation alongside reimbursement applications of technologies have been the main facilitator of the use of economic evaluation at the national level in some

countries.[5, 211, 212, 213] For instance, pharmaceutical companies in both Australia and one state in Canada (Ontario) are formally requested to support reimbursement for pharmaceuticals with economic evaluation data.[214, 215] Evidence suggests that the Australian Pharmaceutical Benefits Advisory Committee (PBAC) uses economic evaluation in making recommendations to the Minister for Health about which drugs and medicines should be available on the pharmaceutical listing.[214] However, the potential role of economic evaluation could be developed for reimbursement decisions in other countries.[216]

In the UK, the request for data about the cost effectiveness of new pharmaceuticals and health technologies by NICE has played a large part in advancing the role of economic evaluation. Also in the UK, Health Technology Assessment (HTA) agencies, which provide evaluations of technologies (drugs, medical devices and clinical procedures) through review of the scientific evidence, have opened the way to greater use of economic evaluation. Around a third of the reports published by the HTA include cost analyses or economic evaluation,[217] although the influence of HTA on decision-making is seen as being limited.[218] However, economic evaluation has been influential in specific Government policies,[219, 220, 221] in particular screening policies,[222] for example in mammography[223] and heart disease/transplantation[6, 7] in countries including the UK. However, it is not obvious at all from these papers as to whether policy makers were using the evidence to support decisions that they had already made, and may have needed justification for spending money on them, or whether they had used the evidence beforehand to inform their decisions.

Despite some evidence for use of economic evaluation at the macro level, its actual use is questionable.[174] In particular, there have been several outliers in decisions made by both the PBAC and NICE and there is contention around whether an explicit cost per QALY threshold exists, beyond which NICE are unwilling to pay for additional life years gained.[206, 214, 224] This suggests that the role of economic evaluation is unclear. However, at least within these systems

there is support by the Government for economic evaluation. In contrast, in other countries, the national level has limited interest in the use of economic evaluation as a criterion in decision-making, as in Austria,[225] because of difficulties of implementing this in a social insurance system, and Japan,[226] because of a fee-for-service system and strict price regulation which is seen as being non-conducive to economic analyses. Apart from Austria and Japan, economic evaluation appears to have also been of limited use in national policy in less developed countries,[227] although there are, even in this context, examples where economic evaluation has influenced policy, for example in relation to screening policies and preventative therapies for TB control in Africa.[1]

2.3 *The meso level*

A total of thirty-eight empirical papers (Table 2A at the end of this chapter) were found concerning the use of economic evaluation at the local level in a range of countries (the UK, US, Australia, the Netherlands, Sweden, Germany, Finland, Portugal, France, Norway, Austria, and Spain). The earliest of these studies date from almost twenty years ago. Here issues of sampling and the main findings of these studies are discussed.

a) Sampling

Earlier studies tended to evaluate health economists' and researchers' perceptions of the use of economic evaluation[7, 82, 222, 228] whereas studies after the year 1995 focus on the input of potential users or decision makers. These latter studies included a range of local decision makers (Table 2.2).

Table 2.2: range of local decision makers sampled

Decision maker	Number of studies
Pharmaceutical advisors or pharmacists	11
Physicians, including internists and GPs/family doctors	8
Insurers of medical care (US only)	6
Medical directors/ hospital managers	6
(Senior) managers responsible for purchasing items of expenditure	4

As can be seen from Table 2.2, pharmaceutical advisors or pharmacists, generally in the UK or the US, have been the most frequently sampled group of decision makers.[6, 229, 230, 231, 232, 233, 234, 235, 236, 237, 238] Pharmacists are an important group to study, since they often have to take account of the costs and efficacy of drugs included in their budget. The second most frequently sampled group were physicians, including internists and GPs/family doctors, [221, 231, 233, 235, 239, 240, 241, 242] although six of these studies included physicians in the sample as part of a wider sample of decision makers,[231, 233, 235, 237, 239, 242] and two studies surveyed only physicians.[240, 241] Studies have also involved insurers of medical care,[221, 243, 244, 245, 246, 247] medical directors/hospital managers [231, 235, 239, 243, 248, 238] senior managers either at the Governmental level or local level,[235, 237, 249] and public health managers.[6, 239, 242] Some of these studies involved an organisation delivering care (for example, a PCT or Trust) and the different decision makers within that organisation.[48, 117, 250, 251, 252]

Earlier studies were largely conducted in the US and tended to involve senior managers responsible for major health service expenditure decisions and insurers of health care or pharmacists/pharmaceutical advisers. The study by Drummond *et al*[6] was the first in the UK to evaluate the use of economic evaluation among a range of decision makers and was followed by the European Network on Methodology and Application of Economic Evaluation Techniques (EUROMET) study,[4] covering a variety of decision makers (managers from Government agencies, physicians, hospital pharmacists, hospital managers, and manager's sickness funds or the pharmaceutical industry) from nine European countries (Finland, France, Germany, Norway, Austria, Netherlands, Portugal, UK, and Spain).

b) Important findings

Use

Health economists are, in general, pessimistic about the role of economic evaluation in decision-making.[222] Various studies have suggested that only a third of decision makers have used economic evaluation in their decision-making.[7, 235, 249] Use is not restricted to one particular type of decision-maker, but among pharmacists,[230, 232, 234] doctors and managers within hospitals,[239] and medical directors or GPs.[248] Interestingly, there have been no studies assessing whether evidence from economic evaluation has actually stopped something from happening.

From the US perspective, economic evaluation is most likely to be used by pharmacists to justify adding a drug onto the formulary.[247] However, although a substantial number (90%) of pharmacists apparently think about using economic evaluation, two-thirds (approximately 60%) occasionally act on this information and few (20%) rarely or never do so.[233] Further, although it might be thought that pharmacists under the pressure of managed care would be more likely to use cost-effectiveness information, no supporting evidence for this claim has been found.[230] In the UK, use of economic evaluation is also found to be limited and there is mixed evidence as to the use of option appraisal (performed for public services, considering costs as well as benefits, to determine value for money[253]). Whereas Drummond[174] claims that option appraisal is a form of economic evaluation, McDonald[48] discovered in her study that benefits are not typically quantified in such appraisals.

It is difficult to establish the level of understanding of economic evaluation among local decision makers from the studies reviewed. Those studies which have examined the issue, suggest that most decision makers appreciate notions of scarcity of resources, opportunity costs, and the need to weigh costs and benefits.[248, 254] Among decision makers at more senior, Governmental levels, knowledge appears to be greater[249] as it is among public health doctors[6] than

among other types of decision makers. The explanation for greater knowledge among public health consultants may be two-fold: health economics forms part of the training in public health; and public health doctors are required to use a societal viewpoint which is also more aligned to the basis of economic evaluation.

Barriers to use of economic evaluation at local level

The majority of the empirical studies explored potential barriers or obstacles to using economic evaluation in decision-making and a summary of these barriers are shown in Table 2.3. They have been grouped into three categories: barriers at the organisational level; decision-making level; and research level.

Table 2.3: barriers to using economic evaluation at the local level

Barrier
Organisational level
o Inflexibility of health care budgets
o Political objectives
o Lack of time in process
Decision-making level
o Lack of understanding
o Other objectives (evidence of effectiveness)
o Individual patient perspective vs. population perspective
Research level
o Bias and quality of economic evaluation
o Lack of relevant economic evaluation

Organisational level

At the organisational level, where the PCT or Trust as a whole is affected, because of the context or environment of health care decision-making, there are three constraining factors on the use of economic evaluation: inflexibility of health care budgets; political objectives being more important than the results of economic evaluation; and a lack of time in the decision-making process.

Inflexibility of health care budgets

Inflexibility in health care budgets, associated with the difficulty in releasing money from one budget to another, has been associated with a lack of use of economic evaluation, since financial resources are not easily accessible. This barrier was found particularly, but not only, for hospital pharmacists in the UK.[4, 6, 229, 231] In the EUROMET study[4] inflexibility of health care budgets was ranked as the most important barrier from a potential list of five barriers, across all countries involved.

Inflexibility of budgets is likely to be particularly related to the UK for two reasons. Firstly, traditionally there is a financial divide between primary and secondary care, meaning that (financial) resources do not often flow freely between the two.[48] Due to this inflexibility, an efficient programme development might not be made. Drummond *et al*[6] and Walley *et al*[229] reveal that decision makers ranked difficulties in reallocating resources from secondary care to primary care as the highest barrier to use of economic evaluation. Secondly, in the UK, finances have tended to be fixed and allocated annually, so it is not possible to borrow against future resources[48] (although finances now have a three-year rolling basis). This might result in a reluctance among decision makers to take a long-term view.[229]

Due to budgetary inflexibility, it is likely that immediate costs are important to decision makers in the NHS. Drummond *et al*[6] found that among UK pharmacists, the acquisition cost of medicine was the most important criterion in the formulary listing, although a large proportion of pharmacists (85%) claimed that they would contemplate better outcome against higher cost. Similar findings have been reported in the US among insurers of medical care who have focused on the immediate costs of acquiring technologies rather than any future savings that might be made.[243, 245]

Political objectives

Several studies, mainly from the UK suggest that the requirement to follow national policies can restrict the use of economic evaluation in decision-making.[48, 228, 249, 254] Specifically, Government directives might be of greater importance compared to evidence from economic evaluation. For instance, Weatherly *et al*[254] found that for decisions relating to CHD or cancer, the majority of respondents ranked NSF guidelines as a very important source of external empirical evidence (78%), followed by Government publications (40%), and NICE guidance (37%). Only a third of respondents were aware of economic evaluation being used in the production of HIMPs and the survey found that cost-effectiveness analyses were ranked as very important by only 15%, quite important by 35%, and of limited importance by 29%. About a quarter (24%) felt that economic evaluation should influence the design of HIMPs "very much so", 15% thought it should be of influence "only marginally" and most believed that it should be of influence "quite a bit". On the other hand, where economic evaluation agrees with national policy it is likely that the research will be adopted. Nixon *et al*[250] found that structured abstracts from NHS EED, which claimed that assertive community treatment (ACT) for those with mental health problems is more effective and also less costly, resulted in the introduction of two ACT teams. In this case, there was also a recommendation from the Government to provide ACT.

Lack of time

Lack of time in the decision-making process, restricting the ability to gain access to economic evaluation or conduct economic evaluation, has been highlighted as a barrier to use in countries including the UK.[228, 243, 249, 254, 255] Often health care decisions need to be made quickly[249] in reaction to immediate problems or unexpected requests for additional funding,[256] whereas time is needed to conduct economic evaluations or for them to become available.[228] It is difficult to deduce from these findings, however, whether lack of time would be a barrier to using research evidence or whether it is particularly the case for economic evaluation.

Decision-making level

At the individual decision-making level, there are three constraining factors on the use of economic evaluation: lack of understanding of economic evaluation; evidence of effectiveness rather than cost effectiveness being important; and the tendency to take the individual patient perspective rather than the population perspective.

Lack of understanding

The EUROMET study defined the extent of training in health economics as being "low": around a third of decision makers surveyed had previously received training.[4] This lack of training in health economics might explain why decision makers are found to have a limited understanding of the techniques of economic evaluation.[4] Further, some decision makers appear to be prone to mistakenly associate cost-effectiveness with cost reduction.[239] On the other hand, often economic evaluations do not readily lend themselves to being used. Technical concepts or jargon typically used in economic evaluation might not facilitate understanding among local decision makers.[231, 249] Duthie *et al*[231] found that, for statements commonly generated in economic evaluation, those related to QALYs in particular were not understood, as has also been reported in other studies.[4, 232, 238] In addition, it could be that economic evaluation itself is too complex for decision makers to comprehend. McDonald presented to the local level an economic analysis (for an open access echocardiography service for the diagnosis of heart failure), consisting of a crude estimate of costs and benefits, but it was not used because it was felt to be too convoluted.[48]

Evidence of effectiveness

Decision makers might attach importance to other objectives, besides allocative efficiency,[6, 223, 257, 258] so that efficiency becomes only one of several influences on decision-making. Evidence of effectiveness has been found to be more important to decision makers than evidence about cost-effectiveness,

particularly among decision makers with clinical responsibility or those in a pharmacy role. [221, 229, 231, 246 238, 259, 260] For instance, MCOs apparently evaluate drugs on clinical efficacy and daily acquisition costs, with little attention to the overall cost-effectiveness.[261]

Laupacis argues that most highly effective drugs are cost-effective, and most marginally effective drugs are not, suggesting that clinical effectiveness is the most important factor.[262] Clinical evidence is often used, without costs, perhaps because the latter is not a priority for clinical day-to-day decision-making.[221] This might account for why Duthie *et al*[231] found that economic arguments that were most commonly understood by GPs related to clinical benefit. Evidence about clinical effectiveness also appears to be the most important factor for GPs and medical directors when deciding whether to adopt a new treatment.[4] On the other hand, there is evidence to suggest that GPs are not as cost averse as might be assumed. In a postal survey of almost two-hundred GPs, Ryan *et al*[263] found that whilst GPs often had inaccurate perceptions of costs, their prescribing habits were influenced by these perceived drug costs.

Individual patient vs. population perspective

Physicians (hospital doctors and GPs) typically base their decisions on the individual patient[4, 48, 231, 240, 241] and are therefore prone to be reluctant to take a population perspective. Thus, the use of economic evaluation appears to enter into a decision-making process constrained by a doctor-patient relationship. In a survey of one thousand physicians in the US, Ginsberg[241] discovered that the vast majority (72%) believed it was the responsibility of the physician and the patient to decide what is cost-effective. These findings are replicated in the UK, where most GPs appear to have a patient perspective in their decision-making: "We don't deal with populations, we deal with individual patents" (Duthie *et al*, page 153[231]). In this study, although in theory GPs accepted the notion of the greatest good for the greatest number, they did not appear to base their decisions on this. Part of the reason for such responses might be because GPs tend to underestimate their role in allocating resources.[4] In contrast, other

decision makers, such as those responsible for allocating funds locally, have been found to be more likely to take a wider societal perspective, or the "population out there" (Duthie *et al,* p.153[231])

Physicians might also have ethical and moral dilemmas associated with rationing care on the basis of economic evaluation. For instance, some physicians in Austria and Portugal are reluctant to refuse treatment on the basis of health economic arguments.[4] In the US, the vast majority of physicians object to the use of cost-effectiveness in screening decisions on moral grounds.[240] "Shroud waving" (or appealing for funding based on emotional criteria, such as 'This patient will die if they do not receive treatment') by clinicians, can deter the use of economic evaluation because such arguments again might not consider a wider population.[228]

Research level

At the research level, constricting factors are related to the studies themselves, including the bias and quality of economic evaluation and lack of relevant studies.

Bias and quality of economic evaluation

Decision makers in several countries have claimed that they are reluctant to use economic evaluation funded by the pharmaceutical industry.[4, 6, 229, 230] The EUROMET study found this to be the second most important discouraging factor among a range of decision makers.[4] It was also found to be the second most important barrier specifically among UK primary care prescribing advisors.[229] Fears of bias in studies funded by the pharmaceutical industry might be well founded, since manufacturers' estimates of ICERs have been shown to be consistently lower than those from academic centres.[264] Economic evaluation also might be perceived as being biased because of a large number of assumptions (regarding the quality of life, timing of costs and benefits, and the discount rate).[4, 238, 254] In one US study, of pharmacists and medical directors,

one of the most important barriers to using pharmacoeconomic research was the reliance on excessive assumptions in studies.[238]

In other cases, the quality of economic evaluation may be perceived as being questionnable[249] or variable.[265] A literature review conducted on the use of economic information in drug selection by hospital formularies found that lack of methodological quality of economic evaluations was the most important barrier.[266] In one UK study, this was found to be an important obstacle in over half of decision makers sampled, from a range of backgrounds, although it was the most important obstacle in only 12% of those included in the study.[6]

Lack of relevant economic evaluation

Few studies have examined the relevance of the topics in economic evaluation to local health care decision-making. Where this factor has been found, it has been suggested that local decisions were rarely made on topics addressed by economic evaluation.[256] One explanation for this might be because medical interventions are more comprehensively evaluated than non-medical interventions[267] which could mean that for decisions on the latter, no appropriate study can be found. Even for medical interventions, however, economic evaluations may well be lacking. For instance, in the US, a systematic search discovered that only two cost-effectiveness studies, relating to the same drug, were available for nine recently introduced drugs of relevance to pharmacists.[230] There could be economic evaluations that would be useful for decision-making by pharmacists, but they are unavailable.[247]

There is also evidence that the perspective of the economic evaluation is a constraining factor to use. Economic evaluation is usually not from the point of view of the local setting, but from a wider societal perspective, which might not be seen as being applicable.[4, 4, 174, 230, 243] Generalizability of studies might be low because of differences in health systems across the settings,[268] although there are potentially other reasons limiting usefulness such as differences in costs and patient populations in local setting compared to society.

Increasing the impact of economic evaluation

Although health economists may not believe that findings from economic evaluation should be the only influence on decision-making,[269] they are concerned to increase its impact and practical use so that economic evaluation has more prominence in health care decisions. Several ways in which the use of economic evaluation might be enhanced have been proposed, with many of these in reaction to the perceived barriers. In this section, four broad factors proposed to increase the impact of economic evaluation are reviewed: generating appropriate incentives (to ensure economic evaluations are timely and relevant and to generate better understanding of economic evaluation); maintaining methodological standards in studies (to address possible criticisms of bias and quality of economic evaluations); using a 'simpler' process, as in cost-consequence analysis; or using economic evaluations as part of a wider process, as in Programme Budgeting and Marginal Analysis (PBMA). Cost-consequence analysis and PBMA can potentially tackle a range of problems associated with use of economic evaluation, including political objectives, evidence of effectiveness, lack of understanding of economic evaluation, bias and relevancy of topics of economic evaluation.

Incentives

It has been recognised that incentives are needed for decision makers to use economic evaluation. There are three general approaches which have been proposed: training decision makers in health economics; active dissemination strategies for studies; and the use of financial incentives. Firstly, training in health economics has been identified as a way to facilitate greater use of economic evaluation.[4, 252] The EUROMET study found that, overall, decision makers wanted more explanation of the results of economic evaluation.[4] Secondly, active dissemination strategies to promote economic evaluation (such as interactive websites, including NHS EED and the Cochrane Collaboration) might be a specific way to increase use. Finally, it has also been proposed to attract decision makers to using economic evaluation by offering financial

incentives.[169, 270] However, it is not clear how this would work in practice given that financial incentives are likely to be only one among many incentives. Also, this raises the question of the sustainability of financial incentives in the long run.

Incentives for health economists to make their work more relevant have not, on the whole, been recognised. A potential problem exists in that researchers, including academic health economists, might view publication in peer-reviewed journals as their main aim, rather than how their work affects the decision-making process.[8, 269] Indeed, recent advancements in cost-effectiveness research by health economists have largely focused on methodological refinement, such as techniques to handle uncertainty in cost-effectiveness measures and the value of information methods,[271] rather than any attempts to make their work utilisable by decision makers. In this respect, Kernick may be correct when he points out that "it is time to move on rather than refine theory further" (Kernick, p.314[272]). By this he means that it is important to encourage conversation between decision makers and health economists, rather than to focus on improving the methodological rigour of economic evaluations which he believes is unlikely to influence 'real' world decision-making.

Maintaining methodological standards

The need to maintain methodological standards in economic evaluation has been widely recognised, particularly among health economists themselves.[2, 3, 8, 236, 251, 265, 273] Reinhardt believes that economic evaluation may generate suspicion due to the assumptions typical in models. He therefore proposes that evaluations should be subjected to "rigorous and penetrating audits that are customary in financial accounting" (Reinhardt, p.555[168]). Others focus more on the concepts and terminology (and standardisation thereof) employed in studies to enable transparency of the findings.[3]

Improvements in methodology may, however, be insufficient to increase use of economic evaluation.[8] Adherence to methodological and reporting practices

was found to have improved in published CUAs over the period 1976 to 2001,[274] although findings in the previous sections suggest that there has been no corresponding increase in the use of these studies. One solution, proposed by Drummond, would be to instigate additional reporting requirements, which, to some extent, go beyond methodological standards, including: a description of the relevant patient populations(s); information about the budgetary perspective and impact on budgets; inclusion of data on costs, consequences, and cost-effectiveness by subgroups; information about the practical implications of adopting the recommendations of the study; listing the key assumptions and data sources; and inclusion of a sensitivity analysis using the decision maker's own data and assumptions (rather than the economists).[236] This would enable the data to be broken down into more relevant areas, such as cost-effectiveness by subgroups (assisting sufficient sample size).

Cost-consequence analysis

It has been argued that CBA in a "disaggregated form",[275] also referred to as cost-consequences analysis,[178] can be more useful in decision-making. [275, 276] Here, different options, using costs and consequences, are contrasted in tabular form. Apart from allowing decision makers to compute their own values in order to take account of the local context (for instance, the impact of a new treatment on lifetime resource use, costs and health outcomes for an individual or group of patients[277]), it also permits other information, such as need and equity, to be presented as well.[276] This enables decision makers to use their local data on costs and benefits and different options to be contrasted clearly and explicitly[276] without prescribing a weighting system.[277] In addition, implications for equity, need, and other relevant objectives can be presented.[276] Cost-consequence analysis might be useful in overcoming decision makers' need for more explanation of the practical relevance of results, as suggested in the EUROMET study[4] and avoid extensive use of assumptions as typical in economic evaluation. It differs from Drummond's suggestions for improving methodological rigour in the sense that the data is presented in tabular form and can be amended and appended to by decision makers. However, some

economists are strongly critical of the approach, regarding it as a 'step back in time'.[278]

PBMA

As a systematic and explicit approach to priority setting, PBMA is a way of "thinking"[279] about economic concepts, rather than a single approach to priority setting.[112] It has been described as a "tool kit"[112, 279] by some, but actually appears to be more of a "framework":

It is not in itself a tool of appraisal or evaluation but rather it represents a means whereby appraisal and evaluation are facilitated.
(Mooney, p. 379[280])

The technique has been described as moving from a "purely economic technique concerned with measuring marginal costs and benefits, to a management process still based on economic concepts but which contributes to strategic planning"(Donaldson and Mitton, p.76[112]).

The objective of a PBMA exercise is two-fold. The first step, programme budgeting, involves establishing how resources are currently being used and can be seen as a way of evaluating total resource usage.[112] The idea is to link cost and activity data to answer such questions as "what proportion of the current budget is going to care of the elderly?"(Mooney, p.379[280]). The purpose of asking such questions is to reflect on the process of decision-making, and be aware of, what Mooney calls, "ad hoc decisions on minor changes in resource allocation" (Mooney, p.379[280]), for instance:

Given the question of whether or not to appoint a new consultant paediatrician, it is extremely difficult for an AHB[vii] to answer other than yes. But if, perhaps with the aid of programme budgeting, an AHB has previously decided to give increased proportion to care of the elderly and mentally ill and handicapped and a lower priority to child care it is better placed to consider the merits of the appointment.
(Mooney, p. 379[280])

[vii] Area Health Board (Scottish), which can be compared to a PCT in England, as an organisational body responsible for commissioning of local care.

The second step is marginal analysis, which addresses how any changes in resource use can be made, either through redeployment, reduction, or expansion of services. Thus, marginal analysis involves comparing the candidates in terms of costs and benefits.[131] Marginal analysis is therefore the point at which economics enters into the process of priority setting.

PBMA can be used: at the micro level within programmes of care (such as cancer services); across services within the same general area of care (such as surgery for a range of conditions or diseases); and across all programme areas within a single health organisation (for instance at the level of the entire services provided by a PCT). The decision rule is to implement the programme if the benefits of allocating £X to a particular programme exceed its opportunity costs.[281]

Arguably, in the UK, PBMA is becoming a more popular method and Table 2B at the end of this chapter provides a summary of research undertaken in PBMA, focusing on the UK (the list is by no means exhaustive). Although many Governments introduced PBMA during the 1960s and 1970s, the interest in the technique then largely faltered[282] and re-emerged around the early 1990's.[112] There has been greater applicability of the framework and the approach has been used almost ninety times in over seventy health organisations in seven countries, with the vast majority (80%) being undertaken between 1992 and 2003.[112] Use of the PBMA approach has been at a wide (macro level) as in local authorities in Australia, which still appear to be using the framework,[283] or at a smaller level, for instance within a specific departments (*e.g.* surgery) within hospitals.[284] In the UK, recently a workshop was held in Wales to determine whether its use could be facilitated at the local level.[285] In other local settings, the PBMA approach might already be undertaken, but in no structured way.[286] In the study by Cohen, the findings from the PBMA he was involved in were incorporated in a strategic plan, and he comments that "this is probably the first time that applied marginal analysis has directly influenced strategic planning in

the United Kingdom" (Cohen, p.7[287]). However, other PBMA studies have not examined or reported the outcome of the exercise on the policy process, often because the work is still ongoing.[288, 289, 290, 291]

Arguably, the achievement of PBMA might be far greater than that of published economic evaluation, since realisable changes can be made.[292, 293, 294, 295] PBMA facilitates a close collaboration between researchers and decision makers, which might generate use of economic evaluation among decision makers.[169, 273] PBMA has also been shown to aid an explicit priority setting basis and the involvement of clinicians, which has been found to be important to the priority setting process.[292, 293] The technique has most often involved discussion groups with decision makers and some PBMA exercises have used Participatory Action Research (PAR), which aims to create knowledge through experience and the action of 'doing'.[279] Where this technique was used in Canada,[292] participant observation, focus groups and interviews were conducted to develop and implement a priority setting approach at the macro level, which released $45 million (Canadian dollars), available for service growth areas and the deficit.

However, there are barriers to using PBMA including a lack of trust between stakeholders to carry out changes (interestingly, trust is not usually a concept recognised by economists), as well as facilitators such as high level champion (which involves an influential person pushing forward the use and continuation of PBMA).[112] These barriers and facilitators can relate to the uptake by an organisation of an explicit approach to priority setting. Successful implementation of PBMA necessarily hinges on the organizational context of decision-making.[296]

c) Methodological appraisal of studies

The empirical studies evaluating the use of economic evaluation in local decision-making have employed a wide range of methods, some of which are able to provide a greater contribution to understanding than others. This section provides a summary of the methods used as well as a discussion of the

strengths and limitations of methods employed. This will help formulation of the methods used in the empirical work in this thesis, as explored in the next chapter.

Methods used

The range of methods employed is presented in Table 2.4. They include postal surveys,[6, 7, 82, 222, 228, 229, 233, 234, 235, 240, 241, 244, 245, 254 259, 297] structured interviews,[249] semi-structured interviews,[221, 231, 235, 237, 239, 243, 252] review of documents,[48, 117, 237, 239, 250, 254, 265] telephone surveys,[230, 232, 238, 246, 247, 260] focus groups, [235, 236, 251]participant observation,[48, 252] and 'researchers own experiences'.[265] Most studies have used only one method: only six employed a combination of methods, such as interviews, postal surveys, and focus groups. [4, 48, 237, 239, 252, 254]

Table 2.4: methods of study

Method	Number of studies
Postal survey	16
Interviews (face-to-face: structured or semi-structured)	9
Review of documents/ documentary analysis	7
Telephone survey	6
Focus groups	3
Participant observation	2
'Researchers own experiences'	1
In depth interviews	0

The most popular method has been postal surveys, typically undertaken in the US. All interviews have been face-to-face, although some have been structured (as in a standard quantitative interview, to gain answers to exact questions, as typical of telephone surveys, also used), whereas others have been semi-structured, permitting greater flexibility in, for instance, the ordering of questions and freedom of responses. Reviews of documents have also been used, whereby documents of interest (such as case studies of decisions made or

local documents) are reviewed to highlight whether some evidence of interest is found. Focus groups, a form of group interview that uses communication between research participants to generate data, have been popular in the UK and Europe over the past few years. Participant observation and documentary analysis, whereby researchers participate in an activity and observe individuals or a group and examine any documents referred to or used, has only been used twice so far. None of the studies used in depth interview techniques, a formalisation of ordinary conversation whereby the interview is discursive, there are no fixed set of questions, instead allowing the interviewee and interviewer to explore an issue.

Strengths

The empirical work conducted has three strengths. Firstly, the majority of studies attempted to explore use of economic evaluation from decision makers' or potential users' perspectives, rather than researchers' perspectives. The work performed on researchers[7, 82, 222, 228] is unlikely to reflect the decision-making that actually takes place. The second strength is that the studies have each used several different methods between them and research has been conducted in twelve countries. In this respect, the EUROMET study[4] appears to be the most comprehensive since nine countries were sampled and three different methods employed. It might be anticipated that use is, to some extent, context dependent, so studies covering a variety of health systems are useful in suggesting commonalities or generalizability. Finally, the studies have sampled different decision makers including pharmacists, physicians, public health managers, insurers, hospital managers, as well as more senior managers. Studies sampling one particular decision-making group cannot hope to capture the range of decision-making at the local level and the findings will not necessarily be applicable to other groups.

Limitations

There are four limitations to the research conducted so far, meaning that its usefulness in exploring the topic is constrained.

Researchers' assumptions

The methods used have largely sought to answer questions based on specific hypotheses, relying on researcher's assumptions related both to decision-making and the use of economic evaluation. Typically, a well-defined decision-making situation, a decision that needs to be made, and decision makers who are able to implement decisions, are all taken for granted. This points to a classical rational model of decision-making. There has also been a general lack of description of the decision-making process. The vast majority of studies did not describe the local decision-making context, perhaps because the main application of economic evaluation is seen at the central level.[236] There is one exception: McDonald[48] described the decision-making environment at the local level, including the process of decision-making, the context, and the actors involved.

With regard to use of economic evaluation, it is typically assumed that evidence can be used directly, as in a problem solving or knowledge-driven way. However, the range of definitions of use referred to in the previous chapter suggests that there is likely to be a diverse range of use of economic evaluation: it can potentially be used to justify existing policies and practice; lead to, or contribute to, a change in policy or practice; inform planning of services; influence the amount of funding available to an area; or highlight important knowledge gaps.[1]

The assumption that research is only directly used can clearly raise unrealistic expectations about the direct influences of research while underestimating the other benefits, in the form of understanding and changes in behaviour and opinions among decision makers. The failure to acknowledge the indirect use of economic evaluation is likely to underestimate its usefulness in decision-making.[298] Solely examining direct use ignores cases which prevent an action from not happening ("fallacy of activity"); findings that are changed or altered in the political process of decision-making ("fallacy of specificity"); studies

being used over time rather than immediately ("myopic fallacy"); and the behind the scenes input of economists where there is no visible link between the production of a study and its use ("fallacy of the invisible input").[298]

Few studies have concerned the contribution of employing health economists to help decision makers in their commissioning decisions,[48, 265] or how well health economic information (such as QALYs) is understood.[231, 232, 236, 250] Further, few studies [234, 239, 243, 244, 246, 254, 255] have addressed use of non-research evidence as well as economic evaluation. This definition of use focuses attention on health economists' views, in the way they would like economic evaluation to be used:

Research in various countries suggests that economic evaluation is not being used by health care decisions makers to the extent that ***health economists think*** *that it should be.*
(Ross, p.103,[249] emphasis added)

Limitations of surveys

The second general limitation of the studies concerns the use of survey methods. Surveys can only capture what decision makers *claim* they do. However, often what people say and do is likely to be different, because the way individuals think they act is not necessarily the way they behave. For example, a study by Drummond *et al*[6] found that a number of respondents claimed to have seen two fictitious studies. In another US study involving telephone interviews with medical and pharmacy directors, there appeared to be inconsistencies in what was being claimed by respondents.[238] In this study, almost all respondents claimed to have an adequate understanding of pharmacoeconomics on the one hand, and yet most terms, such as QALYs, were not understood. The use of survey techniques explains why the most common methods to elicit barriers to use of economic evaluation involve either decision makers ranking choices from a list[4, 6, 229, 235, 260] or selecting choices on a list.[234, 254] Furthermore, quantitative use of survey methods tends to ignore negative or deviant cases (where some findings do not conform to the overall pattern of responses). For instance, one study analysed the responses for the 86% of

participants who felt that pharmacoeconomic data were always or very often used, whereas the 6% who felt otherwise were seemingly dropped from the analysis. The authors did not attempt to explore why these respondents felt differently.

Awareness of respondents of focus of research

In all studies decision makers were aware of the focus of the study and/or that health economists were conducting the study. Policy makers might be inclined to state that they do use research evidence, because they think this is what they should be saying.[299,157] Informants may well, therefore, have had an incentive to be overly positive about the use of economic evaluation and report what they think they *should* say, rather than express their actual beliefs. For example, since the decision makers involved in the research conducted by McDonald[48] were aware of her background as a health economist, it is possible that they acted differently and made a deliberate attempt to use economic evaluation during the CHD meetings she observed.

Health economists incentives ignored

None of the studies have investigated incentives among health economists to produce utilisable work at the local level. This, however, is likely to be important:

> *An equally valid explanation of the growth of published studies is that there has been an increase in the supply of health economists, who need to fill their time somehow.* (Drummond, p.3[174])

Are health economists interested in the use of economic evaluation because they feel that their work is valuable and should be used, or are they mainly interested in enhancing their career? Perhaps health economists and decision makers have entirely different preferences, as well as different perspectives on the world of health care provision.

3. Conclusion

In the UK, economic evaluation tends to be constrained largely to use at national, rather than local, level decision-making. Use of economic evaluation might often support the Government's screening policies (although, in practice, studies have not examined how evidence has been used and whether it might be a justification for something that policy makers had wanted to pursue in the first place). At the local level, there appear to be barriers relating to the organisation, the actors involved, including decision makers and health economists producing research. It is not clear how such barriers might be overcome, and there appears to be a divided camp amongst health economists in terms of those who believe that there needs to be greater training of decision makers in health economics, or involvement of health economists in decision-making and those, on the other hand, who would argue that health economists can stand back and only by improving their work can it be used. This latter group appear to have the most influence on the discipline currently since most health economics work is focused on developing increasingly technical work.

However, in the studies evaluated in this chapter, use of economic evaluation at the local level is generally taken to mean direct use, which would explain why a quantitative figure of 30% use has been found in some studies. In addition, the decision-making process has generally not been explored, although as suggested in the previous chapter, the organisation and decision-making surrounding the NHS is likely to affect the use of evidence. The complexity of decision-making might explain why health economists have deterred from involving this in their analysis, but the methods used have also been unsuitable for exploring the process.

The studies reviewed in this chapter have major limitations. Further research is required on this topic because it is not entirely possible to understand the use of economic evaluation fully here. In particular, it would be important to be able to assess how/whether evidence from economic evaluation, as well as economic

concepts and ideas, are influencing the process of decision-making and in what way they are being used (directly or indirectly). It is likely that more qualitative techniques, including in-depth interviews, which have not been used so far to address this topic, would be extremely helpful. This idea is further developed in the next chapter.

Table 2A: empirical studies about the use of economic evaluation in decision-making

Author(s)	Sample	Methods and sample size	Study focus	Main findings
Alban (1982)[222]	Researchers involved in economic evaluation (Scandinavia and UK)	Postal survey (11)	To explore the impact of researchers' studies on decision-making	Only screening studies had an impact on decision-making. Economists were pessimistic about the role of economic evaluation in decision-making
Alban (1987)[82]	Researchers involved in economic evaluation (Scandinavia and UK)	Postal survey (28)	To revisit/retest ideas from previous pilot study (above)	The interest in economic appraisal as apparent in the UK in 1982, had spread to Scandinavia. Five studies were found to have a major impact (3 were from the UK)
Ludbrook (1986)[228]	Researchers involved in economic evaluation (UK)	Postal survey (46)	To assess the use, and lack of use, of economic appraisal in decision-making	Use of economic appraisal is limited. It is used to support a particular course of action or decision already made
Davies *et al* (1994)[7]	Health service researchers (8 European countries)	Postal survey (87)	To locate economic evaluations, examine the methodology used, and identify use in decision and policy making in health care	Around a third (27%) of studies were thought to have influenced decision-making or policy
McNamee and Godber (1995)[265]	Two HA's (UK)	Researchers personal experiences	To evaluate the contribution of two health economists providing cost effectiveness information about health care interventions to the local level	Cost effectiveness information is of variable quality and difficult to interpret. Usually clear answers are required to answer quite specific questions, for which economic evaluation is not helpful
Ross (1995)[249]	Senior managers responsible for major health service expenditure decisions (Australia)	Structured Interviews (34)	To explore use of economic evaluation from the point of view of potential users	There is a high level of awareness of economic evaluation among decision makers and some had used it in their decision-making. However, there were various barriers to use (including lack of availability of data and expertise)

Author(s)	Sample	Methods and sample size	Study focus	Main findings
Luce and Brown (1995)[243]	Decision makers from hospitals, HMOs, third-party payers, and self-insured employers (US)	Semi-structured interviews (48)	To evaluate the role of economic evaluation in technology assessment in health care	Role of economics is "ambiguous" in the process. Hospitals are particularly focused on traditional financial analyses. Pharmacy committees tend to conduct more economic analyses. HMOs and insurers exclude economics. Barriers were related to the paucity of timely, relevant, and credible information, and the societal perspective of studies
Steiner *et al* (1996)[244]	Insurers (US)	Postal survey (231)	To examine the information used by medical directors of private health plans to make medical coverage decisions for new medical technologies	There was limited role for economic evaluation because of lack of timely data
Steiner *et al* (1996)[245]	Insurers (US)	Postal survey (159)	To investigate the influence of organisational structure and physician's method of payment on managed care plans' decisions to cover new medical technologies	Four of the top five important considerations in deciding coverage of medical technologies related to clinical issues rather than to economic evaluation
Walley *et al* (1997)[229]	Pharmaceutical advisors (UK)	Postal survey (178)	To assess the attitudes of advisers to economic evaluation and perceptions of barriers to cost effective prescribing	Economic issues were less important than clinical issues, but were considered at most meetings between advisers and primary care medical practitioners. Barriers included the lack of credibility of evaluations and structural inflexibility in the NHS
Sloan *et al* (1997)[230]	Directors of hospital pharmacies and pharmacists (US)	Telephone survey (103)	To determine whether hospital pharmacies under the pressure of managed care were likely to ensure less	Hospitals under the pressure of managed care were not more likely to use cost-effective practices. Barriers included a lack of timeliness of studies, lack of

Author(s)	Sample	Methods and sample size	Study focus	Main findings
			costly and more effective provision of care	relevant information, lack of independent sponsorship, and inadequate expertise in economic evaluation
Lyles *et al* (1997)[246]	MCOs (US)	Telephone survey (51)	Mainly to understand the role of socio-economic assessments (which includes cost-effectiveness) on drug adoption decisions	A high percentage of plans used some type of assessment, with clinical effectiveness most common, and cost-effectiveness second. Studies need to be comprehensive and timely if they are to be used
Drummond *et al* (1997)[6]	Medical and pharmaceutical advisors, hospital directors of pharmacy, directors of public health (UK)	Postal survey (446)	To explore the reasons for the lack of impact of economic evaluation	One of main barriers was budgetary inflexibly. There is a need to increase decision makers' awareness of economic evaluation and help them understand study results
Duthie *et al* (1999)[231]	GPs, hospital doctors, Trust business managers, hospital pharmacists, HA personnel (UK)	Semi-structured interviews (17 duo)	To determine the application of economic outcome measures	The use and value of health economics as a discipline is generally recognized. However, there are structural and operational barriers. The latter includes the tendency to focus on the individual level, rather than the population level
Evans *et al* (2000)[238]	Medical and pharmacy directors from MCOs (US)	Telephone survey (41)	To find out the use of pharmacoeconomic and quality of life information in formulary decision-making	Efficacy and safety information were ranked the most important data sources for medical and pharmacy directors. Both groups ranked cost-effectiveness data third. Almost all felt that they had an adequate understanding of pharmacoeconomics, but less than 30% said that they understood QALYs. The main weaknesses of pharmacoeconomic research were perceived to be the reliance

Author(s)	Sample	Methods and sample size	Study focus	Main findings
				on assumptions and the lack of generalizability of the findings
Cox *et al* (2000)[232]	Pharmacists (US)	Telephone survey (16)	To evaluate the relevance of health economic information to decision makers	Statements reported in terms of QALYs were difficult to understand
Grizzle *et al* (2000)[247]	Managed care decision makers (US)	Telephone survey (31)	To understand how pharmacoeconomic information is used in managed care	The majority (>70%) of decision makers felt there was pharamcoeconomic information that they desired but was unavailable to them
Motheral *et al* (2000)[233]	Pharmacists or physicians (US)	Postal survey (409)	To understand how decision makers view and use pharmacoeconomic information	While 90% consider using this information, 20% rarely or never act on this information and two-thirds occasionally do
Anell and Svarvar (2000)[234]	Members of formulary committees (Sweden)	Postal survey (210)	To identify information used and decision-making criteria important in establishing clinical practice guidelines	There was an interest shown in economic evaluation. However, barriers included: lack of competence among committee members; inadequate supply of relevant studies; difficulty in translating results into clinical practice guidelines
Ginsberg *et al* (2000)[241]	Hospital physicians (and family doctors) (US)	Postal survey (1,000)	To identify physicians' views and experience of using cost-effectiveness in clinical decision-making	Most physicians regard cost-effectiveness as an appropriate component of clinical decisions. However, 72% felt that only the physician and patient should decide what is cost-worthy
Rosen (2000)[239]	Hospital clinicians, hospital managers, purchaser managers, public health consultants, others (nurse managers,	Semi-structured interviews (51) and documentary analysis	To explore the way in which doctors and managers view effectiveness of health care interventions and how this affects the evidence they use	Primarily clinicians and public health doctors use cost-effectiveness information, since it rarely relates to decisions made by managers, although the way in which they used published

Author(s)	Sample	Methods and sample size	Study focus	Main findings
	audit officer, regional scientific officer) (UK)		in decision-making	research varied considerably. The evidence used to inform decisions reflects the professional role and objectives of decision makers, such as clinical, financial, personal, and organisational
Hoffmann (2000)[4]	Government agencies, physicians (includes GPs/ family doctors), hospital pharmacists, hospital managers, and sickness funds/pharmaceutical industry representatives (Finland, France, Germany, Norway, Austria, Netherlands, Portugal, UK, Spain)	Postal survey (968), semi-structured interviews (53), and focus group (20)	To assess the extent of knowledge, use, and barriers to use, of economic evaluation	Economic evaluation studies are not widely used in decision-making. Barriers included budgetary inflexibility and lack of credibility of studies. An explanation of the practical relevance of studies, as well as training of end users in health economics is required
Burns (2000)[242]	Purchasers of health care (in UK included non-medical Health Authority purchasers, public health physicians, and GPs) [UK and US]	Semi-structured interviews (55)	To determine the role of HTA and clinical effectiveness information in decisions about health care contracting and purchasing	Purchasers use HTA information sporadically. This appears to be mainly due to inability to access information (in terms of obtaining information and understanding information). Although many UK purchasers were familiar with HTA information, most US purchasers were unsure about what it was and tended to confuse it with other types of information, such as performance indicators
Kulsomboom *et al* (2001)[259]	Pharmacy directors of teaching hospitals (US)	Postal survey (166)	To determine the criteria for using pharmacoeconomic data for formulary decisions, to describe the data sources	The two most important criteria for the use of pharmacoeconomic data were the impact a new medication might have on institutional costs and anticipated annual

Author(s)	Sample	Methods and sample size	Study focus	Main findings
			that were used, and the quality of data	pharmacy budget for a new medication
McDonald and Baughan (2001)[256]	Nine HAs (UK)	Semi-structured interviews (9)	To explore the role of health economists at the local level	The environment of decision-making, which involved reacting to immediate problems or requests for additional funding, is very important. Much of the work conducted by health economists comprises work not related to economics. Rarely were decisions made on topics addressed by published economic evaluations. Economics was sometimes treated as a fur coat to support decisions already made
Folakemi *et al* (2002)[260]	Hospital pharmacists (US)	Telephone survey (204)	To explore the use of pharmacoeconomic data in hospital formulary decisions	The majority (86%) of pharmacists indicated that pharmacoeconomic data were used either all the time or at least very often when formulary decisions were made. Only 6% said that pharmacoeconomic data were rarely or never used. Drug efficacy was ranked among one of the most important factors in formulary decisions
West *et al* (2002)[297]	Senior bureaucrats in provincial governments (5 Canadian provinces)	Postal survey (Not specified)	To examine the procedures for the scientific evaluation of drugs in listing for reimbursement	Information required for decision-making about cost-effectiveness of drugs is often not available. There are also minimal mechanisms to examine cost-effectiveness of a drug once it is listed: hence, there is no way to re-visit a decision once it has been made
Weatherly *et al* (2002)[254]	Health Improvement Programme (HIMP)	Postal survey (102), telephone	To explore the use of evidence (economic evidence	Government reports and reports from NICE were the main sources of published

Author(s)	Sample	Methods and sample size	Study focus	Main findings
	leaders, HAs (UK)	interviews (10), and documentary analysis	in particular)	evidence, rather than economic evaluation. Barriers include lack of time and availability of studies. Accessible summaries of studies may facilitate greater use
Nixon *et al* (2002)[250]	One HA (UK)	Documentary analysis	To explore how summaries of clinical and economic evidence can be accessed and used in local decision-making	Findings from structured abstracts from NHS EED suggested that assertive community treatment (ACT) tends to be more effective and also less costly. Two ACT teams were subsequently introduced
McDonald (2002)[48]	One HA (UK)	Participant observation and documentary analysis	An exploration of the nature of local decision-making and the role of economic evaluation in Coronary Heart Disease (CHD) strategy	Rational health economic approaches are unlikely to be adopted widely due to the political environment, existence of competing objectives, and lack of explicitness in decision-making process
Johnstone and Lacey (2002)[117]	One HA (UK)	Documentary analysis	To investigate decisions based on evidence of effectiveness from Randomised Controlled Trials (RCTs) and systematic reviews of RCTs	Evidence existed for less than half the decisions identified (124 in total). For 42 decisions, favourable evidence to support the decision was identified; in 18 decisions the evidence either showed equivocal benefit or no support; 64 decisions had no clear evidence from economic evaluation
Hoffmann *et al* (2002)[251]	Range at HA (UK)	Focus groups (2 in total)	To examine the usefulness of economic evaluation to the decision-making process	Decision makers generally recognized the usefulness and necessity of published economic evaluation in informing the decision-making processes. However, there was a poor generalizability of the results and lack of methodological rigour

Author(s)	Sample	Methods and sample size	Study focus	Main findings
				in studies. There was a general consensus among decision makers in favour of developing a quality scoring system for studies
Drummond *et al* (2003)[236]	Managed care pharmacists (US)	Focus group (10)	To discover how health economics information can be used	Seven additional reporting requirements were specified for economic studies
Ubel *et al* (2003)[240]	Hospital physicians (and family doctors) (US)	Postal survey (560)	To determine the influence of cost effectiveness information about physicians' screening decisions	Providing cost effectiveness information had only a moderate influence on physicians screening recommendations. 36 physicians' indicated cost was not relevant to medical decisions
Ijzerman *et al* (2003)[221]	Local decision makers, including GPs, representatives of health insurance companies, members of the Health Insurance Board, and medical guidelines committees (The Netherlands)	Semi-structured interviews (not specified)	To discover whether pre-assessment of decision makers' needs can increase the impact of economic evaluation	Use of economic evaluation is not "self-evident." Cost effectiveness criterion is of limited importance; results from clinical effectiveness studies and budget impact studies are of greater importance
Sheldon *et al* (2004)[237]	Primary care prescribers/hospital pharmacists, senior clinicians and managers (UK)	Semi-structured interviews (68) [Also time series analysis and audit of patients notes]	To assess the extent of implementation of NICE guidance (12 cases)	Implementation of NICE guidance has been variable. It is more likely to be adopted where there is strong professional support, a clear evidence base, and no increased costs
Williams *et al* (2005)	Committee members	Documentary	To address the extent to, and	At the local level, economic evaluation

Author(s)	Sample	Methods and sample size	Study focus	Main findings
252	(local level, including representatives of Trusts and PCT, and NICE committee members) (UK)	analysis, meeting observation, and semi-structured interviews. Five case studies were conducted in total: including committees from four local and one national (NICE)	ways in, which health economic information is used in health policy decision-making, as well as the factors associated with utilisation	rarely informs technology coverage decisions (although at the national level, the opposite was true, and economic analyses were found to inform technology coverage decisions). The main sources of information on cost-effectiveness were found to be the manufacturers of product information and NICE guidance. Barriers related to: limited resources and capacity to generate or locate evaluations in time to inform decisions; inability to realise savings identified in analyses; concerns about bias due to the source of the analysis, the robustness of the analysis or the appropriateness of the comparators. These problems arose within an overall context of a lack of incentives to use economic analysis and a lack of skills and understanding. To facilitate greater use, there is a need for a clear, standardised format for the presentation of economic analysis including greater clarification of the assumptions that went into models. Health economic analysis could be improved by making it more sensitive to the questions that health provider's need answers to. Training in health economics is also required

Table 2B: empirical studies about the use of PBMA in decision-making

Author(s) and publication date	Study setting	Selected services considered	Main findings
Cohen (1994)[287]	One HA (Wales)	Range, focusing on maternal and early child health services	There was an agreement to incorporate the findings into the strategy plan
Bellamy and Kluvers (1995)[283]	Local government (Australia)	Range	A majority of councils said that they would use the traditional budgetary approach, irrespective of whether they were using programme budgeting
Craig *et al* (1995) [290]	One HA (Newcastle)	Range	Work was ongoing
Brambleby (1995)[289]	Two local authorities within a HA (England)	Range	Useful in terms of communication and education, but work still undergoing
Twaddle and Walker (1995)[294]	Health Board (Scotland)	Gynaecological services	There was an agreement to incorporate findings into contracts
Ratcliffe *et al* (1996)[288]	Health board (Scotland)	Range	Effects of implementation were not reported
Rutal *et al* (1996) [295]	Health board (Scotland)	Child health services	Recommendations were incorporated into policy, resolving difficulties and apparent conflicts facing purchasers
Peacock (1998)[293]	Hospitals (South Australia)	Range	Research achieved realisable changes in services based on the principles of CEA. Also achieved a change in decision-making culture and acceptance of range of matters in planning services
Mitton and Donaldson (2003)[292]	Macro level clinicians and managers (Canada)	Range	Study built upon the PBMA framework and released $45 million (Canadian dollars), available for service growth areas and the deficit

Mitton *et al* (2003)[284]	Hospital (Canada)	Surgery	One of two of the recommendations from the PBMA was implemented. The other failed to be implemented because a lack of financial resources to fund the proposal

Chapter 3: Research methodology and design

Chapter 2 suggests that further exploration of the use of economic evaluation in health care decision-making is required. There is currently little knowledge about the extent to which economic evaluation is used, particularly in terms of indirect use, and existing studies have tended to employ relatively insensitive quantitative techniques. Choice of methods is therefore crucial to enhancing knowledge in this area rather than merely repeating existing work. This chapter discusses the rationale for using qualitative research methodology in exploring the research topic. The chapter begins by examining the basis of qualitative research (in terms of ontology, epistemology, and methodology) before investigating the research design and specific methods used here to explore views of decision makers and health economists. The final section of this chapter presents a brief conclusion.

1. Ontology, epistemology, and methodology

Different perspectives can be taken in any research, and hence different paradigms and points of view employed, as suggested here. These are typically in relation to positivist and interpretative research paradigms.

1.1 Paradigms in research

A paradigm characterizes changes in the "standards governing permissible problems, concepts and explanations" (Kuhn, p.106[300]). A paradigm forms the implicit beliefs, values, and commonsense assumptions of a scientific community, and in this respect a paradigm is more than a set of theories. For instance, the development of Newton's physics marked the emergence of a new paradigm in physics. Although paradigms cannot be proved or disproved, they represent fundamental positions that are taken on the part of the researcher.[301] Denzin and Lincoln[302] relate paradigms to particular ontologies, epistemologies, and methodologies. These terms along with others are summarised in Table 3.1, with each concept informing the next.

Table 3.1: concepts associated with research paradigms

Concept	Description
Ontology	The study of the nature of existence or reality
Epistemology	The theory of knowledge (which addresses the relationship between the researcher and the known)
Theoretical perspective (or paradigm)	The philosophical stance informing the methodology and hence providing a context for the process
Methodology	The plan of action or design lying behind the choice and use of particular methods
Methods	The techniques used to gather and analyse data related to a research question or hypothesis

(Crotty, p.3-10[303])

Two distinct research paradigms (positivist and constructivist/interpretativist) will be explored in detail.

a) Positivism

The ontological stance of positivism is a belief in realism, or some single knowable reality, which is based on the natural sciences.[302] An example in economics, is the belief in general equilibrium theory. This means that behaviour, institutions and society can be studied in the same way as, for instance, a chemical process.[105] For positivists, research is based on empirical observation and hypothesis testing, leading to a rejection or acceptance of the hypothesis, where researchers aim to be objective, seeking to uncover 'facts'.[304] For instance, positive economics is used to describe the branch of economics that deals with description, based on facts confirmed through empirical evidence.[105] Popper, an advocate of realism, whose work forms much of social science thinking, suggests a "falsification" method, in which a statement is scientific if it is testable, rather than whether it is true or false.[305, 306] These views have been adopted by Blaug, an economist who suggests that a theory cannot be proved to be true and it is only possible to disprove it.[307] However, it is disputable whether the social world can be studied as the natural world can be, due to the complex interaction of people, with differing views, thoughts,

and opinions. Lawson, a contemporary (critical) realist economist, believes that complex social structures, as studied by economists, require more flexible approaches.[308] Lawson argues that the main problem with economics is that the method used does not reflect the nature of the phenomenon:

Rather than starting with a question about an aspect of social reality and determining an appropriate method, modern economists usually start with a particular type of method and presume, mistakenly, that it must be appropriate to all social contexts. The result is that modern economists end up distorting social phenomena just to render them open to treatment by their chosen approach.
(Lawson, p.22[260])

Lawson argues that economic modelling, with its reliance on functional relationships, is largely inappropriate to studying most social phenomena.

b) Constructivism/Interpretivism

As a result of the inadequacies of positivism to define social situations, qualitative research has arisen as a separate methodology in its own right. Qualitative research has been defined as:

A multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people give to them.
(Denzin and Lincoln, p.3[302])

Although the types of qualitative research studies are diverse, employing a multitude of methods, qualitative research has particular characteristics (Table 3.2).

Table 3.2: characteristics of qualitative research

Theme	Description
Naturalistic inquiry	The study of natural or real-life situations as they unfold and openness to findings that emerge
Design flexibility	Willingness to adapt inquiry as understanding deepens and/or situations change
Qualitative data	Thick, rich descriptions based on direct quotes of people's individual perspectives, detailed observations, careful document review, or case studies
Dynamic systems	Assumes change is constant and ongoing
Personal insight	The researcher has a close relationship with the people and the situation, and hence the researcher's personal experiences and insights are an important part of the understanding of the phenomenon
Inductive analysis	Exploration of patterns and themes in data, followed by confirmation, guided by analytical principles as opposed to rules
Holistic perspective	Focus on the whole phenomenon under study, where meaning cannot be reduced to a few discrete variables

(Patton, p.40-41[309])

The majority of qualitative research is conducted within a constructivist framework,[302] also referred to as interpretative inquiry, naturalistic inquiry or hermeneutics, because it deals with the interpretation and understanding of text.[310] Constructivist inquiry has also been associated with theoretical perspectives such as symbolic interactionism (interpretation of other's actions are based on the meaning which they attach to such actions[311]) and phenomenology (which describes people's experience, without recourse to theory or assumptions from other disciplines[105]). Constructivists believe that people 'construct' knowledge based on their experience, history, and culture, which recognises subjective meaning and not objective reality. They oppose the notion that it is possible to directly grasp the 'real world' through empirics and they believe that no one 'truth' exists.[310] Hence, behaviour is not self-evident, from what people say and do, and requires interpretation.[312] Consequently, qualitative research, conducted within a constructivist framework, aims to gain an 'interpretative' understanding of subjects' meanings.[312]

The constructivist paradigm is based on a relativist ontology (as opposed to realism) and knowledge is created through the researcher and the research subjects, so that there are multiple realities.[313] This paradigm has a 'subjectivist' epistemology, which suggests that the interaction between subject and 'object' creates the form of inquiry.[301] However, not all qualitative researchers are fully supportive of the notion of relativist inquiry and Hammersley proposes a weaker version of realism, termed subtle realism, which is:

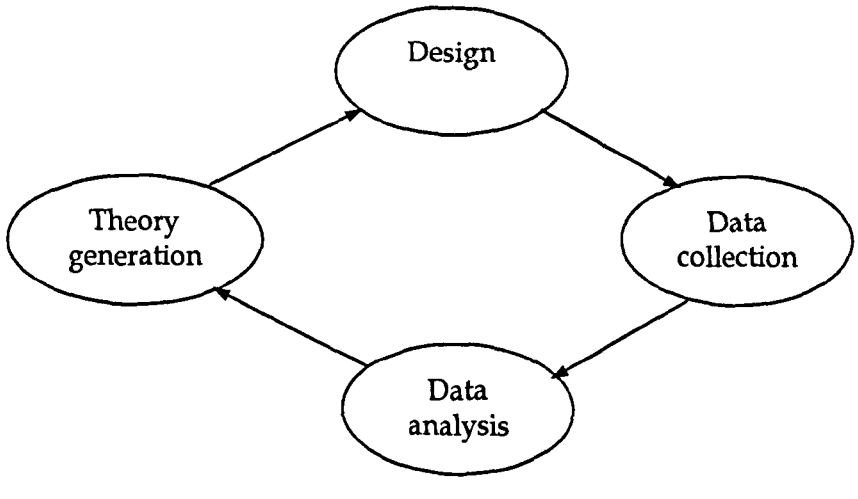
...the idea that research investigates independent, knowable phenomena. But it breaks with [realism] in denying that we have direct access to those phenomena, in accepting that we must always rely on cultural assumptions, and in denying that our aim is to reproduce social phenomena in some way that is uniquely appropriate to them. (Hammersley, p.52[314])

The constructivist paradigm typically uses methodologies such as ethnography and grounded theory.[303] All attempt to understand people's worlds, although there are marginal differences in foci. Ethnography is a method of studying and learning about a person or group of people in their own environment, paying particular attention to culture. Grounded theory, as described by Glaser and Strauss, has a slightly different perspective in that it refers to how to build *theory* which is developed inductively from a body of qualitative data.[315] Hence, grounded theory aims to understand phenomena by being 'grounded' in the data and developing thick, rich descriptions of people's behaviour or views.[315] The approach involves reading (and re-reading) a body of data (such as field notes) and exploring emerging concepts or categories, as well as any interrelationships, with the purpose of developing new theories.[315] Grounded theory also stresses the importance of simultaneous data collection and data analysis, so that the process is iterative.[315] Grounded theory was subsequently expanded on by Strauss and Corbin[336] who provide four central criteria for 'good' grounded theory: 1) it should fit the phenomenon, which has been carefully derived from diverse data; 2) it should provide understanding, and be comprehensible to those within and outside the study; 3) it should provide

generality, being applicable to a wide variety of contexts in the area; 4) and it should state the conditions under which the theory applies and provide a basis for action in the area. Inevitably, different interpretations of grounded theory arise from thse two works, neither of which provides empirical application. For instance, where Stauss and Corbin suggest that theory should be applicable to a variety of contexts, it is not clear from Glaser and Strauss's work that this is the case and there appears to be more focus there on developing a theory that accounts for much of the relevant behaviour.

Blaxter[316] suggests that methodologies such as grounded theory, which typically involve inductive theory development[viii], can be diagrammatically represented as an entire research process (Figure 3.1).

Figure 3.1: inductive theory development



(Adapted from Blaxter, p.8[316])

Inductive theory development enables exploration of, and reflection on, the phenomenon, where the design influences data collection, data analysis, and theory generation. This occurs in a cyclical fashion, so that following theory generation, for instance, the design of the project is altered or modified, leading to further data collection.

[viii] Note that the standard approach in positivism is deduction, which refers to a series of logical steps in deducing conclusions from, for instance, generalization or universal law.[105]

Health economists tend to be largely unfamiliar with qualitative methods. Where health economists have used qualitative research it has tended to inform quantitative analysis,[85] using questionable qualitative methods. For instance, in the study by San Miguel *et al*,[85] the authors claim that qualitative analysis was where "an open space was provided for...responses within the questionnaire" (In press). Coast has argued that qualitative research is a challenge for the discipline of health economics, based on two premises: the acceptability of methods and the acceptability of presentation.[317] In relation to the former, health economists are accustomed to assessing the quality of research in terms of generalisability, whereas this is not a requirement of qualitative research. Indeed, a recent article suggested that most economists view fieldwork (or qualitative research) as a "doubtful activity, one reserved for the lowest orders, such as reporters and sociologists" (The Economist, p.64[318]). However, the article goes onto profess the "fruits of fieldwork" and that "data is just the plural of anecdote - as long as the anecdotes are scrupulously and systematically chosen" (The Economist, p.64[318]). This suggests that economists have most trouble with the small number of participants in qualitative research, whereas typically quantitative research uses large numbers. In addition, reflexivity (whereby the researcher attempts to assess their influence/perceptions on the research process/findings), highlighted as an important attribute of qualitative research,[302] is likely to conflict with the idea of objectivity. In the latter case, typical in economic studies, it is assumed that there is a single version of reality that cannot be influenced by the perceptions of the researcher. Hence researchers' influence on the data/subjects is not examined (this might explain why the studies on the use of economic evaluation did not consider the potential influence of participants knowing that health economists were performing the research).

Despite the challenges that qualitative research presents to health economists, qualitative techniques are likely to become more important in areas such as attribute development for discrete choice experiments in health economics[319]

(although the exact way of proceeding with this remains unclear), as well as in more exploratory studies such as reported in this thesis.

1.2 Methods in qualitative research

Many methods of data collection are available for use in qualitative research, including interviews, participant (or non-participant) observation, focus groups, documentary analysis, and content analysis of questionnaire materials (whereby usually pre-determined categories or themes are fed back into quantitative models[317]). The remainder of this section focuses on interviews, participant observation, and documentary analysis, which are the methods that were chosen for this research. Focus groups were not used because it was felt that they rely on a hypothetical scenario and would be difficult to convene without appearing contrived. Questionnaires were also not used because they are relatively insensitive to exploring views and options about a complex topic such as health care decision-making.

Whatever method of data collection is chosen, the method of sampling is important, and it is to this area that this section turns first.

a) Sampling

Sampling (or choosing a smaller group or entity) is necessary because it is rarely possible to study an entire population.[320] There is a distinction between qualitative and quantitative sampling strategies. Quantitative studies typically use samples selected randomly, and of sufficient size to achieve a pre-determined level of statistical power, and are most appropriate when the purpose is description and explanation.[321] Quantitative sampling is also concerned with representativeness, so that the results of studying the sample can be generalized back to the population.[320] In contrast, qualitative studies typically focus on relatively smaller samples, selected purposefully, using non-random selection, and are most suited for exploration and theory development,[321] including questions of 'why?' and 'how?'[320] Statistical representativeness is usually not a feature of qualitative research.[322]

Furthermore, qualitative sampling tends to be (although not always) iterative, so that more data can be collected after theory refinement. Hence, the sample size is usually not pre-determined, becoming clearer only as the study progresses and the new categories or themes cease emerging from the data (saturation).[315, 320] Since the focus is on information richness and quality, sample size in qualitative research is not crucial for the study.

As the sample size is usually not pre-determined, the choice of sampling strategy needs to take account of the context of the study as it evolves.[320] There are various sampling strategies available to the researcher, depending on the objectives of the research, including theoretical sampling, maximum variation sampling, and snowball sampling.

Firstly, theoretical (or purposeful) sampling, associated with grounded theory,[315] involves collecting data as theory emerges - hence, new samples are sought to elaborate on the data already collected. The analyst selects informants, collects and analyses data, with the aim of producing a theoretical explanation before deciding which data to collect further and from whom.[323] The purpose of sampling is to refine ideas or explanations and researchers might revisit the same settings or individuals to gain further information.[313] Some qualitative researchers suggest theoretical sampling later in the research process in particular enables insights to be developed.[313]

Secondly, maximum variation sampling is a special kind of purposeful sampling, which involves obtaining a broad range of perspectives on a subject.[324] The objective is to select cases that exhibit maximal differences between each other in the cases of interest. Finally, snowball sampling entails identifying informants from other informants already sampled.[304] Snowball sampling is commonly used when potential informants are not known to the researcher and are difficult to find, but are known to informants in the area.[304]

In practice, a mixture of sampling strategies are likely to be used, since, for instance, purposeful sampling may mean going outside of a group sampled based on what has been suggested by informants (resulting in snowball sampling). All of these sampling strategies, however, are likely to differ from obtaining a simple convenience sample (or selecting whoever is closest or easiest to sample), since this is unlikely to obtain a full range of views or opinions on the topic.

b) Data collection

Interviews

Interviews are usually conducted to uncover the subjective meanings of informants' experiences and views and to allow exploration of complex issues.[325] Interviews are a useful technique for collecting data which would be unlikely to be accessible using other methods.[316] Interviews can be in-depth (referred to also as exploratory or unstructured) seemingly equivalent to a guided everyday conversation,[310] or structured, which are similar to questionnaires, in that informants receive the same set of questions, using a structured interview schedule (or a list of points/questions to be raised), and questions are asked in the same order.[326] Semi-structured interviews are a mixture of both types, in the sense that interviews are generally unstructured but researchers have a pre-determined list of points that they aim to cover during the interview, although these points can be raised in any order.[327]

It is important to note that the choice of interview type undertaken will largely depend on the research and the information being sought.[310] For instance, structured interviews are used in public opinion polls and market research,[328] where the objective is to obtain a wide response. In contrast, in-depth interviews are most appropriate when developing ideas and research hypotheses.[328] In-depth interviews offer the possibility for researchers to be deeply engaged in the development of the project[328] (hence, it appears, relating closely to the iterative model in Figure 3.1).

During in-depth interviews the onus of conducting a 'good' interview is essentially on the interviewer. The interviewer must be able to pick up what is being said, what is being omitted, and the hesitations expressed, together with the reasons behind them.[328] At the same time, the interviewer must also create a neutral or relaxed atmosphere, to enable the informant to express ideas in their own words.[328] The researcher must therefore be involved in collecting ideas rather than only data, and ideally there is a constant monologue by the informants on the topic of the research, and limited role for the interviewer - using nuances (such as "Uhuh") or prompts (such as "Yes", "I see", or "Please go on").[328]

The method of conducting interviews (face-to-face or telephone) is also important because this can affect the type of data collected. Although face-to-face interviews are the usual, telephone interviews are becoming a more important tool for data collection. They tend to be cheaper to organise and easier than face-to-face interviews and some have claimed that informants tend to stay more focused on the topic.[327] The disadvantages of telephone interviews are that potentially important nuances may be lost and it is not possible to provide visual prompts (for example, eye contact, to signal awaiting a reply or interest in what is being said).[327]

Rapport and trust are essential for all interviews, irrespective of the type and method by which they are conducted.[326] In particular though, in-depth interviews require a high level of interpersonal skills, such as the ability to put informants at ease, asking questions in an interesting manner, and jotting down informants' responses without interrupting the conversational flow.[328] In-depth interviews are usually recorded on tape,[310] to capture accurate details of what is said[328] and to also allow the interviewer to concentrate on the process of the interview.[316] It is important that the interviewee trusts that the interviewer will keep the information imparted on the audiotapes confidential.

Reflexivity is also a key feature of interviews. It is necessary for the interviewer to reflect on their experience and role within the research[325] so that potential improvements can be made to the interview technique, the quality of the interview can be assessed, and insights developed (again relating to the iterative process as shown in Figure 3.1).

Participant observation

Participant observation enables exploration of how the context of a social situation gives meaning to behaviours or beliefs.[329] It contrasts with the interview technique because it does not rely on the perceptions of informants, but offers the researcher an opportunity to directly access people's assumptions.[329] Importantly, it can allow differences between actual behaviour (in a certain situation or setting) and verbal behaviour (during interview) to be examined.[329] Further, participant observation offers the opportunity to examine *sequences* of events, rather than attempting to piece together understanding from interviews.[329] The technique is particularly suited to studying the working of organisations and how people perform their roles.[330]

Prior to conducting participant observation, it is necessary to gain access to the setting. This might be particularly difficult, since formal settings are not easily penetrated and can be policed by 'gatekeepers', who themselves might not be readily known.[331] Gaining access can therefore be an important part of the process and can take time. Once access has been obtained, the degree of participation depends on the purpose of the study and the nature of the setting[329] and can vary (during the course of the fieldwork), from complete participation to non-participation (or complete observer), although most fieldwork lies between these two extremes.[329]

During observations, researchers usually take 'fieldwork observations'. These typically concern the following categories, although they might not be recorded in a single observation: noting who is present and the 'activity' that is happening, including when, where, and why it is happening.[329] Spradley

differentiates between three types of observation depending on the stage of the research.[332] These three levels can be thought of as a funnel, where each level has a narrower focus: descriptive observations tend to occur early in the study; focused observations, which are more selective than descriptive observations, tend to occur in the 'intermediate stages'; and selective or highly focused observations occur towards the end of the research when more insight has been gained. Following observations, it is important for the observer to be reflexive and to constantly ask questions about the way their presence is influencing what is being observed and the findings from the study.[331] This is relevant for the ideas generated as the study progresses.

Documentary analysis

Documents are essentially any written text, and for the purposes of research, they are a social product in the sense that they are produced on the basis of certain ideas, theories, and principles.[126] Scott[333] suggests that quality control criteria should be used to assess authenticity (how genuine the document is), credibility (how distorted the document is, in relation to truthfulness), representativeness (in relation to the body of documents), and meaning of documents. The latter is of importance since although positivistic researchers tend to look for facts and figures, it is necessary to go beyond this and examine the actual meaning of the document, which might be bound up with the subjectivity of the author or researcher.[304] Apart from the actual data provided in documents, documentary analysis can also be important for triangulation (*i.e.* checking whether a similar picture emerges as from other methods of data collection).[126] This can confirm what is already known or provide insights not generated previously.

c) Analysis of qualitative research data

Different methods of data analysis are typically used in qualitative research, including framework, content analysis, discourse analysis, and conversation analysis. Those methods that do not use an iterative approach are not further considered here. The iterative approach involves: affixing codes to field notes or

interview transcripts; noting reflections; identifying relationships, patterns, themes, and differences between groups; taking these patterns or differences to the next wave of data collection; and theory generation.[334] Miles and Huberman propose that analysis consists of three continuous and iterative activities: data reduction; data display; and conclusion drawing/verification.[334] These are discussed in turn.

Data reduction refers to the process of "selecting, focusing, simplifying, abstracting, and transforming the data" that appear in field notes or transcripts (Miles and Huberman, p.10[334]). An important part of data reduction is the creation of codes, which refers to making meaning of blocks of text.[335] Grounded theorists suggest a careful line-by-line reading of text to enable codes to be 'grounded' in the text.[336] There are essentially three recognised types of codes[336] (usually but not always in this order): 'open coding' or categorizing of the data; 'in vivo' or identifying categories and terms used by informants; 'axial coding' or putting the data back together by establishing connections between categories. For example, in assessing the attributes for older people's preferences for dying, open coding of the data might reveal factors such as 'relationships', 'family', 'burden', 'place of death', *etc.* Some of these categories might be terms used by informants. Axial coding establishes links between the codes, so that for instance, following on from the example of people's preferences for dying, relationships could be a general theme, encompassing family and friends. Under family could come the desire of older people to ensure their family are well provided for when they die, on the one hand, and also their wish not to be a burden on their family should they develop cognitive or physical impairment.

As coding categories emerge, the researcher compares and contrasts concepts, using 'constant comparison', whereby accounts are compared with one another to facilitate richness in data analysis, between different types of respondents or settings.[315] Following on from the example above, views of different types of older people might be compared and contrasted, depending on: their income;

whether they have any disability (cognitive or physical); whether they are in a care home or in their own home, *etc.* The objective is to find out whether a particular view or opinion is likely to be dependent on the type of individual - for example, between those informants at home and those cared for professionally in care homes. Constant comparison involves familiarity with the data through repeated reading, comparison of data to other data and to developing themes, testing of hypotheses whilst generating new data, development, modification and extension of categories, and detailed descriptive accounts. (In contrast, quantitative research has preference for numerical data subjected to statistical analysis,[304] comparing all data at the end stage, with little or no descriptions). To assist the process of comparison and analysis, the researcher may also use memos, of which three types have been described:[336] code notes describe the concepts that are being discovered; theory notes are summaries made by the researcher on his or her ideas; and operational notes concern practical matters, such as the timing of observations and listing who was present.

Once this process is underway, data display is undertaken, involving organisation of information so that conclusions can be drawn.[334] For instance, following on from coding of data, it is useful to use displays (such as matrices, graphs, and charts) to enable the researcher to see what is happening and either draw conclusions or move onto the next stage of analysis.[334] At this point, it can also be useful to generate ideas for testing in subsequent fieldwork. This process can also help to identify negative or deviant cases that disconfirm parts of the analysis or suggest new connections (note that in quantitative research disconfirming evidence is generally ignored[335]). Finally, conclusion drawing and verification of the data, as new data are collected or reviewed, occurs throughout the data analysis.[334]

2. Quality of qualitative research

It is important to be able to assess the quality of qualitative research, although how to do this in practice is a contested issue and there are opposing views between researchers.[331, 337] There are those who believe that the same criteria should be applied to qualitative and quantitative research (*i.e.* reliability, validity, and replicability[ix]).[338] This group believe that qualitative research should be judged using the same criteria as quantitative research and assumes the existence of an underlying reality that can be studied.[337] There are also those, the majority, 'antirealists', who feel that qualitative research represents an alternative paradigm to quantitative research and should therefore be judged by alternative criteria. The criteria Hammersley regards as important to both qualitative and quantitative research are 'truth' (or validity) and 'relevance'.[331] Regarding truth, although Hammersley acknowledges that it is never possible to have access to reality or knowledge of whether an account is true (he is a proponent of 'subtle realism', as discussed previously), he believes that the validity of claims should be judged on the basis of the adequacy of the evidence offered in support of them. It is necessary to provide more evidence in support of central claims, and what is involved in assessing the validity of a claim varies according to whether it is a definition, description, explanation, or theory.[331] Hence, the requirement for validity is likely to vary between cases. Relevance, concerns the importance of the topic and contribution of the findings as relevant criteria (although a mere confirmation of what is already known is of limited value).[331] Although Hammersley is not a proponent of assessing qualitative research on the basis of generalisability, he does suggest the importance of reflecting on the 'typicality' of cases to the general population.[331]

According to Hammersley, assessing the quality of qualitative research should include[331]: the degree of development of theory; the novelty of the claims made; the consistency of the claims with empirical observations; the credibility

[ix] The definitions are as follows: reliability assesses whether the results are repeatable; validity concerns whether the research measures what it says it does, in terms of 'internal' (to the study) or 'external' (to other settings or other populations); finally, replicability concerns whether the results are reproducible.

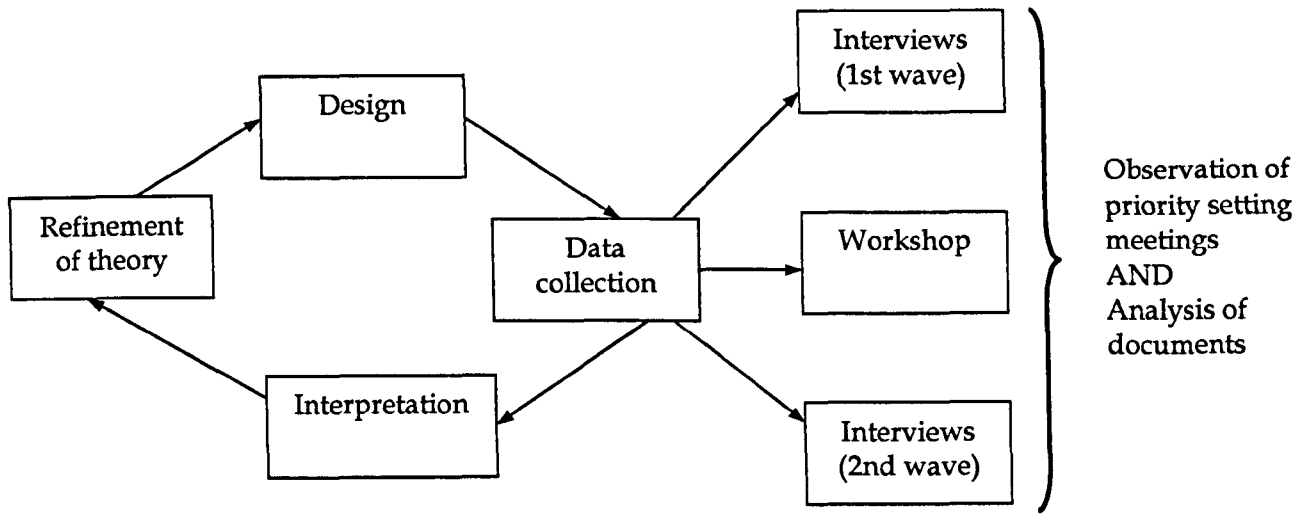
(or truthfulness) of the account; the extent of transferability of the findings to other settings; and the reflexivity of the account, including the degree of assessment of the effects of the researcher and the amount of information about the research process. These criteria are similar to, and agree with, the medical sociology group criteria (in Boaz and Ashby[338]) for assessing qualitative studies and the criteria suggested by Mays and Pope.[337] It is generally recognised that the methods and data need to be explained so that other trained researchers would be able to conduct the study and come to the same conclusions.[330] However, criteria for assessing qualitative research are likely to be open to challenge, since, for instance, it is arguable whether all research should be concerned with the development of theory.[331] Furthermore, assessing qualitative research is likely to be dependent on emerging criteria as "the entire field of interpretative or qualitative inquiry is itself emerging and being defined" (Lincoln, p.275[339]).

3. Methods of study

The theoretical perspective and methods discussed so far are of paramount importance to the study design employed in this research. The choice of whether to use qualitative methods, and the associated tools, depends on the aims of the research, rather than solely the preferences of the researcher[320] (although it is, of course, likely to involve making a particular judgement).[317] This study used a modification of grounded theory, located within a constructivist/interpretative paradigm, using qualitative methods. The design of the study, the fieldwork area and actual methods used, as explored here, reveal the iterative, flexible, and in-depth nature of the work conducted. Local Research Ethics Committee (LREC) approval was obtained in January 2003.

3.1 Design of study of local decision-making

Figure 3.2: study design



The initial stage of the project, which took place over a period of approximately one year, involved observation of a meeting group for cancer care (the CG), documentary analysis, and in-depth interviews. This allowed the researcher to establish rapport with decision makers and to gain substantial knowledge of the decision-making environment and process. Following this, a workshop on economics was held upon the request of the chair of the CG (and was delivered by an outside speaker). The local study therefore differs from what appears, in a quantitative paradigm, to be a 'before and after' study, where an intervention is deliberately constructed. Here, the aim was not to try to determine whether changes resulted from this workshop. Instead, the workshop allowed the researcher to observe decision makers trying to prioritise and subsequently provided the opportunity to explore their feelings about the role of economics in further interviews. Following the workshop, the objective was not to examine whether decision makers had changed their opinion about economics or whether the process of decision-making during the CG had been affected, but to open the way for explicit discussion of economics which had not been previously possible. In addition, the second round of interviews provided the opportunity to re-explore topics which had been generated since the first round of interviews and hence confirm or refute hypotheses. Decision makers who were interviewed in this second round were selected to include those who had

attended the workshop, but also those important to the process of decision-making as perceived by those already interviewed.

The work conducted with health economists comprised a parallel project, involving interviews with senior UK health economists, purposefully selected according to their different roles. The purpose of these interviews was to explore their views of use of economic evaluation in local decision-making in the NHS. This is important since it is necessary to find out how far their views and opinions differ from local decision makers and to be able to reflect on the work being undertaken by this group, since they are the main producer of economic evaluations in the UK.

The fieldwork took place over sixteen months (January 2003 to April 2004). The study design was iterative, so that design, data collection (consisting of interviews, a workshop and observation of priority setting meetings, and documentary analysis), data analysis, and theory development, were informed by one another (Figure 3.2). Although observation of priority setting/CG meetings occurred continuously over the sixteen months, the first wave of interviews (of which 17 were conducted) took place between February and November 2003, and the second wave (consisting of 12 interviews) between March and April 2004. These second wave interviews followed the economics workshop held in January 2004. Prior to the workshop, eleven meetings were observed including eight CG meetings and three hospital meetings (a meeting group attended by hospital representatives of the CG, which fed into the CG).[x] Following the workshop, four CG meetings were observed.

The study used a 'modified' grounded theory approach. Although the main goal was to develop new theories through purposeful and systematic generation of the data, there was a strong interest to try and gain knowledge of the whole field. This idea is similar to ethnography but it is not the focus of

[x] Note that only three hospital meetings were observed because, according to informants and following observation of these three meetings, it became clear that the main decision-making occurred within the CG.

grounded theory (since accurate evidence is not particularly crucial for generating theory and the objective is to develop a theory which accounts for much of the behaviour of interest, rather than providing a perfect description of an area). Decision-making at the local level was studied in depth, over a period of time, through observation of CG meetings. This was particularly important since it was necessary for the researcher to grasp a new area/field and put aside her training as an economist/health economist.

3.2 Selection and entry into fieldwork area

The research was based in one PCT. The location of the fieldwork has not been specified in this thesis to retain informants' confidentiality. There were two fundamental criteria for the selection of the fieldwork area: first, the ability to gain access at the local level to informants; and second, the willingness of local informants to engage in the research once access had been gained. Meetings were observed after initial contact with the chair of the CG. The CG meetings were a formal part of the local service organisation and brought together providers and commissioners to make decisions about the funding and delivery of cancer services for their local population. Although several other groups also existed, such as for mental health and CHD, the CG was seen as a point of entry into the decision-making process for the research.

The provision of cancer services involves primary health care, secondary health care, and palliative therapy. Consequently, those attending the CG meeting included GPs, hospital managers, clinicians, nurses, palliative care managers, cancer network managers, and PCT managers. The meetings were held bi-monthly, for approximately one hour, and usually the same people attended, although over the period of fieldwork new members arrived and some left the group. The remit of the group included decision-making for services related to breast cancer, lung cancer, upper and lower gastrointestinal tract cancer, genitourinary tract cancer, haematopoietic system cancers, head and neck cancers, and other rare cancers. These services are located within secondary

care, in surgical oncology and non-surgical oncology, due to the nature of cancer treatment and speciality provision.

4. Data collection

4.1 Observation

At the start of the first CG meeting attended (in January 2003), participants were informed about the project, to be undertaken by a PhD student, and that any information extracted from the CG meetings would be used only for PhD research. The participants of the CG were asked whether they objected to observation of the CG meetings and were also given the opportunity to ask any questions, although in the event no objections or questions were raised. All members were provided with written information outlining the study (Extract 1 in the Appendix). Participants were also asked for written consent (Extract 2 in the Appendix) to being observed on the understanding that observation would cease the moment that anyone felt uncomfortable (this did not occur in practice). Over time, any new participants to the CG were also provided with the same information, and similarly asked to provide written consent.

Apart from the chair of the CG, informants were not aware of any focus on the use of economic evaluation. The importance of being vague during initial contact with informants in the field has been acknowledged[329], particularly in view of the iterative nature of the research and thus possible changes to the design. In this study, participants were provided with a broad description and overview of the study, stating that the interest was on local decision-making in the NHS. While this statement was true, it was deemed to be less threatening than introducing the interest in use of research evidence or economic evaluation, which could have also influenced informants' actions or decisions in a way that would have both altered the research findings and also have ethical implications (in that, to appear to be doing the right thing, informants might overweigh economic research evidence) compared to their usual practice and thus influence decision-making. However, the importance of being honest is

also well known[329] and any questions on the research were dealt with in an open manner (although, in practice, it was never relevant to discuss the economics component of the study).

Hand-written notes were made during all meetings observed. The CG meetings were not audio recorded because it was felt that this might influence what participants were saying and create an unnatural environment. As much information as possible was jotted into a notepad, but often it was not possible to capture everything that was being said and on some occasions it seemed inappropriate to take notes (for instance, where something clearly confidential or personal was being discussed). Over time, certain themes or topics started to emerge from the data, and the researcher became aware of these whilst taking notes during the meeting, making note-taking a slightly easier process. However, during the first couple of meetings, the researcher needed to adapt to the medical terminology being used, as well as the role of different types of medical drugs and equipment. All information was written down and spellings/understandings were checked later.

Apart from what informants were saying, body language and temperament of the informants was recorded where relevant and often provided important contextual information. Different roles and behaviour were similarly noted. Hand-written notes were typed up as soon as possible after the meeting, usually the same day. The cut off point for observation of CG meetings was determined by the timescale associated with the decision-making framework (in that the formal decision-making framework ran from April of one year to the following April), saturation of the findings, and timescale constraints associated with the study.

4.2 Workshop

The chair of the CG was keen to engage the group in explicit priority setting and proposed the idea for a workshop on economics to participants of the CG.

He appeared to be interested in receiving help in making some of the decisions the CG were responsible for (and, unlike other participants in the study, was aware of the researcher's background as a health economist) and following discussion between the chair, the researcher, and one of the researcher's supervisors (JC), a workshop seemed to be the most appropriate means of meeting the chair's needs. An experienced health economist, being the researcher's supervisor at the time (JB), was responsible for running the workshop. The workshop was held over a two-hour period. All (fifteen) participants of the CG were invited to attend the workshop. In the event, ten attended, including the chair of the CG. The workshop involved a presentation of basic economic concepts, economic evaluation, and PBMA. Prior to the workshop, two health economists (from outside the University of Bristol and with experience of the health service) assessed the appropriateness of the presentation slides, offering some constructive comments. The chair of the CG meeting also examined the presentation slides during a meeting arranged with him specifically for this purpose, although no changes were made as a result. The presentation slides are provided in the Appendix (Extract 3), although some parts, pertaining to the geographical region and details of the priorities, have been anonymised or deleted to retain confidentiality.

During the workshop, the list for funding, which was discussed during the previous months by the CG, was presented and participants were advised to incorporate costs and benefits of the listed programmes into the decision-making process. The presentation was followed by a group discussion during which members of the group were asked to decide which of the programmes were related to the targets or guidance set nationally and which of the programmes had evidence about their effectiveness or their cost effectiveness. They were then supposed to be presented with a smaller list of fourteen non-funded programmes and asked to prioritise them, taking into account their budget constraint, an estimate of the incremental costs and benefits, and what the opportunity cost of each programme might be. However, the chair of the CG also came to the workshop with a revised list of priorities from the CG and

finally these were the ones discussed. The workshop exercise, which was not actually used (because there was a debate on what should be the priorities, hence consuming most of the time), is provided in the Appendix (Extract 4). Again details of the priorities have been deleted to retain confidentiality. An evaluation form (Extract 5 in the Appendix), to assess the quality of the presentation slides and information, was also provided to informants.

4.3 Interviews

a) Sampling

In total, twenty-nine interviews were conducted with twenty different people; thirteen of these were participants in the CG (Table 3.3).

Table 3.3: backgrounds and number of informants interviewed

Role	No. Interviewed	Number who were members of CG
PCT role	8	2
Hospital managers	3	3
Palliative care	2	2
Cancer Network	2	2
GPs	2	2
Nurse	1	1
Clinician	1	1
SHA	1	0
TOTAL	20	13

Prior to the workshop, seventeen single interviews were undertaken with participants of the CG (nine), non-participants/PCT managers (six), and local representatives from the cancer network (two). Initially, informants were purposefully selected from those who had expressed a particular viewpoint in the CG meetings or had failed to contribute to discussions during the CG meetings, to account for any particular views (in line with maximum variation

sampling and to account for negative cases). Table 3A and 3B indicates the reasons for selection of participants. However, eventually the majority of CG participants were interviewed, since important themes emerged and were developed in further interviews. New participants to the CG meeting group were not necessarily interviewed because saturation was reached. Six PCT managers were interviewed, based on snowball sampling and because of the seniority of their role and their importance in decision-making at the whole PCT level. Cancer network members were also interviewed because of recommendations made by those already interviewed.

Following the workshop, twelve interviews were conducted. Informants were purposefully selected on the basis of attendance at the CG (seven) and those who had been invited but were unable to attend (four). Two of these interviews were with informants who had not been interviewed previously because they had recently joined the CG. In addition to these interviews, one interview was conducted with the SHA manager responsible for this locality since it emerged that it would be important to obtain a viewpoint of someone more senior than the PCT. Nine of the interviews were re-interviews with the informants sampled prior to the workshop.

Table 3A and 3B (prior and post workshop, respectively) at the end of this chapter present the role of the informant interviewed, the reason for interviewing them, duration of interview, and comments on the interview. 'S' denotes the subject interviewed and the number represents the order in which the interview was conducted. An extra 'S', as in Table 3B, denotes that interviews were conducted after the workshop (since this aids interpretation in the analysis).

Invitation to interview

In interviews prior to the workshop, members of the sample were contacted by e-mail to ask whether they would agree to be interviewed (Extract 6 in the

Appendix). They were provided with an outline of the study, which emphasised that it was PhD research, and reminded/informed about the nature of the study. They were told that the purpose of the interview was to study decision-making at the local level. They were also asked about the possibility of audio recording the interview. Two of the CG participants contacted declined to take part in interview. One CG participant felt that she was too busy and taking part in an interview would jeopardise personal time. Another informant was commencing maternity leave so could not take part. All PCT managers who were invited to interview agreed to take part.

In interviews following the workshop, informants were again contacted by e-mail but on this occasion they were informed that the focus of the interview was to discuss their use of economic evaluation in priority setting following from the workshop (Extract 7 in the Appendix). The workshop provided an entry into discussions about the use of economic evaluation, without appearing to force the issue suddenly upon informants. Two informants declined to take part in an interview, because of lack of time.

All interviews followed the same general guiding principles. Specifically, the term 'meeting' was used in preference to the word 'interview', to prevent any formal connotations with the event and to help create a relaxed atmosphere. Invitees were given approximately one week to respond to e-mails, after which time they were sent follow-up e-mails or telephoned to find out whether they were available for interview.

Conducting interviews

All interviews with decision makers were in-depth and face-to-face. At the beginning of the interview, interviewees were provided with an information sheet outlining the study and emphasising, again, that it was for PhD research (Extract 8 in the Appendix). Informants were then asked to complete and sign a consent form for interview (Extract 9 in the Appendix). Informants were

reassured that their views would be extremely valuable and would remain confidential. Upon being asked to confirm that the interview could be audio recorded, informants were assured that all data would be anonymised and audiotapes would be kept in a locked, secure unit. The vast majority of interviews (twenty-seven) were audio recorded; one informant refused to be audio recorded and one interview was not audio recorded because of technical problems with the machine. In the latter instance, the interview was not repeated because it was difficult to arrange another interview and hand written notes were therefore deemed to be sufficient.

Informants led interviews, enabling them to discuss the topics that they felt were important. However, interview schedules were used to ensure that some important areas were covered, where appropriate, and to provide stimulus if the conversation faltered. At the beginning of interviews prior to the workshop, informants were asked about their professional role and how they felt priority setting worked in their area. These were general questions, which were found to put the informants at ease and allow more difficult topics to be covered as the interview progressed. The schedule contained prompts on: interviewees' perceptions of the factors they believed to be important in the decision-making process; how and who made decisions; how decisions were communicated to CG participants; whether there was an appeal process for decisions believed to be unfavourable; how decisions were made in other PCT areas or decision-making bodies; and whether they used any evidence in making decisions. As more interviews and observations took place, the interview schedule was adapted to allow for emerging themes. The final interview schedule is provided in the Appendix (Extract 10).

Whereas interviews prior to the workshop took place over a relatively long period (February 2003 to November 2003), interviews after the workshop occurred over just two months (March 2004 and April 2004). Post workshop interviews were timed to allow recollection of the workshop but also a chance to have thought about the ideas and concepts. An interview schedule was used,

again to provide guidance should conversation dry up. Prompts included: the use of economic evaluation by the informant personally or by the CG; the factors that were important to priority-setting decisions; and the barriers or obstacles to the use of economic evaluation, experienced by them personally or the group. The final interview schedule is provided in the Appendix (Extract 11). It should be noted that use of terminology associated with economics (such as cost-effectiveness, QALYs, efficiency, *etc*) was avoided during interview, in order to allow informants to express themselves in any way that they wished.

During all interviews, informants' meanings were continually checked instead of relying on assumptions. Towards the end of each interview, informants were asked whether they wanted to add any comments before the interview ended. Often asking this question tended to lead informants to summarise what they had said during the interview or, more interestingly, encouraged them to raise other topics they felt to be important in greater detail. In addition, following the interview, after the audio recorder had been switched off, some informants continued to discuss the topic, expressing opinions that they did not feel were relevant during interview. These were noted immediately after the interview ended. All audiotapes were listened to the same day and transcription occurred over the next few days. In addition, field notes, which were taken to provide summary information about the setting of the interview and general perceptions of the interview in terms of rapport and ease of responses, were also included as a separate section in the transcript. Again, these notes were used to direct future research and to identify emerging themes, but were also part of the reflexive process.

All interviews were scheduled for one hour, although in practice interviews lasted between thirty minutes and one hour thirty minutes, with the mean interview duration being about fifty-five minutes for interviews prior to the workshop and fifty minutes following the workshop. Most interviews ended naturally, although sometimes informants had other appointments scheduled after the interview so they were unable to spend more time than the allocated

hour even when they wanted to. Interviews were only continued past the allocated hour on the interviewees' insistence. The vast majority of interviews were held at the office of the interviewee; one was held at the informant's home and another was held in the meeting room of the CG, after the meeting had taken place.

4.4 Documentary analysis

Formal documents from the PCT, the CG, option appraisal, and other written material were analysed alongside the interviews and workshop observations. These documents often served to increase the level of understanding of the decision or issue. Most of the time documents did not provide additional information, but supported the decision or issue. The main focus was on assessing the meaning of the documents, paying particular attention to the ideas being expressed, the language used, and the way in which the authors intended the documents to be interpreted.

5. Interviews with health economists

Alongside the fieldwork with decision makers, a separate project took place with a sample of health economists. The purpose of undertaking interviews with health economists was to find out how far their views differed from decision makers since health economists are generally instrumental in producing economic evaluation and also have a role in national and local decision-making (such as through NICE, priority setting forums, and working at the local PCT level as health economists). Their views and opinions shape the conduct and reporting of economic evaluation, and so are important.

5.1 Sampling

Health economists were identified through a specific annual publication on Health Economists' Activities, Research and Teaching (HEART) and through Internet searches. Interviewees were purposefully selected to include: senior academic health economists; those involved in national decision-making (such

as through NICE or the Scottish or Welsh equivalent) or local priority setting forums; and those with local decision-making experience, in PCTs or the equivalent. This attempted to obtain the full range of health economists in a variety of roles. The sampling strategy was based on maximum variation and snowball sampling.

The total sample size (fifteen) was determined by the exhaustion of new themes arising from the research (saturation). Table 3C at the end of this chapter provides the background to the health economists interviewed. Interviewees are labelled E (where E denotes 'economist') and the numbering represents the order of the interview.

5.2 *Invitation to interview*

Health economists were sent, by e-mail, a letter, to ask whether they would participate in a telephone interview for approximately half an hour (Extract 12 in the Appendix). In this letter, they were also provided with a description of the overall study of both decision makers and health economists. If they agreed to be interviewed, they were asked to complete and post a consent form for interview (Extract 13 in the Appendix), which was attached to their e-mail message, together with possible dates they were available for interview. Upon receipt of the consent form, the health economist was contacted by telephone or e-mail to confirm a specific date and time. Where health economists did not respond to the invitation to interview, they were contacted again to ask whether they could take part. Of the health economists approached for interview, five never responded to the original e-mail and subsequent e-mails, and two declined saying that they were too busy or were not the best person to be involved in the study.

5.3 *Conducting interviews*

Interviews were all arranged between March and November 2003. Interviews were conducted by telephone, due to budgetary and time limitations. Informants were reassured that all data would be anonymised and kept in a

securely locked unit. All informants were willing to be audio recorded but in the event two recordings were lost because of a technical fault with the machine, meaning that transcripts are not available for these interviews (E10, E11).

Interviews were semi-structured, because it was necessary to cover some essential points in the limited time. A schedule (Extract 14 in Appendix) was used, although informants were free to guide the interview and points were not covered in any particular order. The schedule included: who they thought the decision makers were; their perceived use of economic evaluation among decision makers at national and local decisions; how economic evaluation is used; and the barriers to using economic evaluation by decision-makers. Questions were angled differently for those not performing many economic evaluations but who have a major influence on the methodology used. In these cases, the topics were more in relation to methodological developments. Again, notes were made following the interviews on rapport and ease of responses. Other aspects that could only be recorded through face-to-face interviews were not noted. Interviews were scheduled with economists for half-an-hour and the mean interview time was forty minutes.

6. Data analysis

6.1 Analysis of observations and documents

Hand written notes from the CG meetings were coded in the same way as interview transcripts. The observations of the CG meetings helped to form an overall picture, whereas the interviews provided specific reflections at a point in time. The observations of the CG meetings therefore helped to provide important information about the decision-making process and context. They also supplemented information offered during interviews. It was interesting to note that the majority of informants behaved very differently publicly during meetings compared to privately in interview. This highlighted the differences

between what people say and do, and hence supported the use of methods triangulation.

Formal documents circulated at the CG meetings (usually funding proposals, product information, or financial data) were analysed and coded at the same time as the observations of the CG meeting, to aid interpretation. Often these documents helped to elaborate on some of the issues further. Moreover, PCT documents referred to in interview by some informants were helpful in showing how the formal decision-making process was supposed to operate in contrast to the process that was actually observed.

The process of data analysis was resource intensive but provided rich and meaningful data. After a few CG meetings were observed, the researcher gathered a list of emerging themes/topics (in some cases these were simply perceptions/notions such as "power" or "funding", and in other cases they were words which members of the CG had used themselves whilst talking, such as "hypothecated sum", which appeared to adequately reflect the ideas being presented). Together with the documents which the researcher had examined during this process, a descriptive account was prepared which detailed the type of issues that were being raised in the meetings, who attended, as well as initial impressions gained. Negative cases helped to form a part of the analysis - hence, for instance, where one informant appeared to have different motivations, feelings or behaviour, this was documented and reasons for these differences were explored, either by re-examining the evidence or through further interviews. Analysis was only considered complete once all negative cases or disconfirming evidence had been accounted for. Other descriptive accounts were prepared for further small numbers of observation transcripts and combined/supported with evidence from interview transcripts, providing a rich source of data which included all the researchers' data collection to date. At later stages, several descriptive accounts were merged into a single document, reducing duplication of themes, and allowing for an overall summary and reflection. This constant and reiterative data collection

and analysis enabled the generation and testing of hypotheses/theory. It should be noted that early in the process joint coding was conducted between researchers (OA and JC). All descriptive accounts were also read by JC, who relayed any comments or ideas back to the researcher. This enabled the researcher and her supervisor to discuss the emerging themes from the data, to share ideas, and resolve any apparent conflicts in the data. Triangulation of coding, whereby two or more researchers separately identify and attach codes/themes to the data, has been suggested as a way of achieving greater reliability in the analysis.[323] Case studies were developed for particular decisions.

Notes from observation of the workshop were analysed slightly differently from the observations of the CG meetings. Observation from the workshop was analysed as a single event that was somewhat disjointed from the CG meetings. Hence there was no prior background to the workshop, apart from the priority list for funding, which was discussed and developed through the CG. Again it was important for detailed notes from observation of the workshop to be made, since the workshop represented an area that future interviews would be developed from. Three completed evaluation forms were also analysed. The observation transcripts from the workshop were combined into the descriptive account, described previously, which was built up over time.

In the findings presented in the following results chapters, observational data and data from analysis of documents are combined with interview data. It is important to note that, as will become apparent, observations from the CG meetings provided important information on the process of decision-making, those who were involved, and the context. Analysis of the observation transcripts provides an overall picture of decision-making and was helpful in addressing important issues in interviews conducted later with informants. For this reason, it may seem that the majority of justifications for the arguments provided in this thesis are from interviews with informants, although various case studies are taken from decisions made during the CG.

6.2 *Analysis of interviews*

Audio recordings were fully transcribed as soon as possible after each interview, to be able to recall any unrecorded data (such as nuances, sarcasm, intonation) and to ensure consistency and permit familiarity with the data. Full transcription refers to an accurate recording of the words spoken, including interruptions, pauses and laughter. Detailed information about the length of pauses, 'umm', 'err', and repeats of words were only noted if they could be meaningful (for example, in the case of hesitation or uncertain reactions). The recorded notes were consistent, so that verbatim was placed in double quotes ("..."), paraphrases in single quotes ('...'), and researcher comments in square brackets ([...]).[329] Transcription usually took between six and eight hours per tape, which is normal.[322] The accuracy of the transcription of the data was crosschecked by re-listening to all audiotapes whilst reading the transcripts.

Analysis drew on the constant comparison method of grounded theory. As discussed previously, data collection and data analysis took place concurrently. This process enabled the development of hypotheses and pursuit of emerging themes. Transcripts were read several times, line-by-line, and sections of the text relating to a specific theme or area of interest were copied and pasted from the transcripts into separate Word documents under relevant headings. Codes, developed from a coding schedule (see Extract 15 and 16 in the Appendix) were then attached to specific sections of text within a theme. Early in the process triangulation of coding was conducted (by OA and JC).As more interviews were conducted, data were examined for similarities and differences. Codes were modified, refined and new codes were added. During the coding process, accounts were generated for small samples of interviewees and all quotes were used relating to a particular theme. As more descriptive accounts were generated, they were combined into one analytical report, which allowed greater comparison and contrast. In conjunction with this process, matrices, involving sub-groups of respondents, facilitated organisation of the data. Here,

columns were used to represent the topics, with rows representing individual respondents. The use of matrices also helped to overcome the problem of finding simplifying patterns that may not exist.

Although the process of data analysis was the same for both studies, transcripts from health economists were initially analysed separately from those of local decision makers, and different themes and codes were developed. However, towards the end of the analysis, a combined analytical report was produced that summarised the differences and similarities between decision makers' and health economists' perceptions and beliefs.

In the thesis, quotations presented are those that best illustrate and support the suggested themes developed, although there were generally several quotes that could have been used. Some quotations were deliberately not used, although they might have been the best illustration of what was being said, in order to retain the confidentiality of informants (particularly for health economists, who are easily identifiable through the area of study they are involved in researching). Quotations were 'cleaned' in the sense that ellipses were used to denote missing speech removed because it was not relevant to the specific topic being addressed. Nuances such as "umm", "err", "you know", "I mean" and repeats of words that do not add to meaning have been removed without the use of ellipses. Underlined words are those that were emphasised by the interviewee. Square bracketed text was used in some cases to retain the confidentiality of a particular person, area, or institution name. Furthermore, in this thesis, quotations are sometimes provided which relate to e-mail correspondences. In these cases, consent has been obtained to use these comments and acknowledgement has been made to their source.

7. Conclusion

Although the methodology in this thesis is likely to be substantially different from that commonly employed by health economists, it followed a protocol for

careful and rigorous data collection and analysis. This study used a modified grounded theory approach, located within a constructivist/interpretative paradigm. This allowed the exploration of a complex setting, enabling the data to 'speak for itself' without the imposition of pre-determined ideas, as has happened with some of the previous research conducted on this topic. For the study of local decision-making, a range of qualitative methods was employed, including observations, documentary analysis, and interviews, allowing information about different aspects of decision-making to be gathered, as well as providing differences between what people say and do. For the study of health economists, telephone interviews with a range of informants were chosen as the best method, within time and money constraints. Throughout the analysis, the researchers' influence on the research was documented. For instance, records were made in cases where it was felt that decision makers were uneasy during CG meetings because of the presence of the researcher (although, in practice, this was not perceived to be a problem), as well as the researcher's role in the workshop (which was important since the chair knew of the researcher's background as a health economist). Reflexivity was also an important feature during interviews with health economists, since the researcher often felt uneasy during interviews with senior colleagues and therefore free-flowing conversation was sometimes restricted. Such recordings of the researcher's influence on the research enabled understanding of the how the context affects the data generated.

Table 3A: pre-workshop: informants' backgrounds and interview descriptions

Code	Sex	Role			Purpose of interview	Time	Comments
		PCT	*Hosp*	*Clinic*			
S1	M	✓		✓	Attended CG meeting. Was vocal in group and represented one of the two GPs attending	1 hr	Good setting, ease of responses and rapport
S2	M	✓			Chair of cancer group	1 hr	Excellent rapport. He invited me to CG meetings
S3	F		✓	✓	Occasionally attended CG meeting and was recommended by S2	1 hr	Good rapport although difficult to obtain responses at beginning because she was worried about confidentiality of what she was saying
S4	M		✓	✓	Attended CG meeting and had quite strong ideas about receiving funding for treatments for his patients	45 mins	Difficult rapport and difficult to conduct. Interviewee was late and was keen to finish in less than the hour slot. The interview was interrupted twice
S5	M	✓			Attended CG meeting and expressed some interesting ideas about organisational culture during meetings	1 hr	Very good rapport and ease of responses. Difficult to maintain conversational flow however because was not audio taped (on S5's insistence) and therefore tried to take notes during interview
S6	M			✓	Recommended by S5 and S2. Attended CG meeting and did not participate much	1 hr 15 mins	Very good rapport and ease of responses
S7	F	✓			Chaired a similar group to the CG meeting. Was recommended by S2	1 hr	Very good rapport and ease of responses. Difficult for me to be at ease because had spent time trying to fix audio recorder
S8	F		✓	✓	Attended CG meeting and was very vocal in meetings	30 mins	She seemed nervous and sometimes not willing to expand on things, but rapport was very good
S9	F		✓	✓	Recommended by S2. Attended CG meeting and was very vocal in meetings	1 hr	Very good rapport and ease of responses

Code	Sex	Role			Purpose of interview	Time	Comments
		PCT	*Hosp*	*Clinic*			
S10	M	✓		✓	Recommended by S5 and S2. Attended CG meeting was one of two GPs attending	45 mins	Very keen to talk a lot, sometimes was difficult to control and keep focused
S11	F	✓			Chief executive of the PCT and recommended by S10 (and indirectly by some others)	45 mins	Very good rapport and ease of responses and seemed very interested in project
S12	M	✓			Chair of the PCT and indirectly recommended by some	1 hr 10 mins	Very good rapport and ease of responses
S13	F	✓			Recommended by S11	50 mins	Very good rapport and ease of responses
S14	M	✓		✓	Recommended by S13	50 mins	Very good rapport and ease of responses
S15	M	✓		✓	Recommended by S12	45 mins	He was very nervous about being interviewed. Interview was difficult to conduct and responses were not freely flowing as in some other interviews
S19	F	✓ (CN)			Recommended by S2	1 hr 15 mins	Very good rapport and ease of responses
S20	M	✓ (CN)			Recommended by S19	35 mins	Very good rapport and ease of responses

Note: CN = cancer network

Table 3B: post workshop: informants' backgrounds and interview descriptions

Study code	Sex	Location			Reason for interviewing	Time	Comments on interview
		PCT	*Hosp*	*Clinic*			
SS1	M	✓		✓	Did not attend workshop and had previously difficulties in priority setting decisions during interview and at CG meetings	30 mins	Interviewee was very stressed because he was so busy. It seemed he wanted to rush the interview and did not find it particularly engaging. Rapport as previously established was there however
SS2	M	✓			Instigated workshop and was a keen advocate of 'rational' decision-making	50 mins	The interview was very relaxed and informal
SS3	F		✓		Did not attend workshop but had discussed use of economics previously in interview	1 hr	Interview was very relaxed. She was worried about confidentiality at the beginning of the interview and stated that she did not know how she could be of help to answer topic of the interview
SS4	M		✓	✓	Attended workshop and had expressed dislike in making priority setting decisions previously during interview and at CG meetings. He was criticised by the chair of the CG about his clinical decision-making	50 mins	The interview went very well. Although he had said that he could only spare 30 minutes of his time at the outset of the interview, he was keen to talk for almost one hour. He was very engaged in the interview
SS5	M	✓			Attended workshop (although had to leave half way during the presentation). He was a key informant from the PCT	30 mins	The interview was held in the corner of the meeting room after one of the CG meetings, so was difficult to conduct in the context. As before, he did not want the interview to be tape recorded
SS6	M			✓	Did not attend workshop but had expressed some interesting ideas about the need for a strategy in the previous interview, suggesting a systematic approach	1 hr 15 mins	Excellent rapport and although he needed constant affirmation that he was talking about 'the right thing' he got further into the topic and discussion was at ease. He appeared to be reluctant to end the interview

Study code	Sex	Location			Reason for interviewing	Time	Comments on interview
		PCT	*Hosp*	*Clinic*			
SS8	F		✓	✓	Did attend workshop and had previously shown aversion to priority setting in secondary care. In the workshop she made some interesting comments	45 mins	Interview setting was very difficult because some maintenance repairs were being undertaken outside and so difficult to hear her at some points
SS9	F		✓		Did attend workshop. Role meant that very responsible for cancer services at the hospital (reports to SS3)	1 hr	Interview was very relaxed. She expressed concern at the beginning of the interview that she would not have anything to say on the topic of the interview though and seemed initially pre-occupied with this feeling
SS10	M	✓			Did not attend workshop and had expressed some dislike in making priority setting decisions in primary care previously during interview and at CG meetings	55 mins	Interview was relaxed and friendly, although was interrupted by a lengthy telephone conversation half way through
SS16	M		✓	✓	Attended workshop and was one of the only ones in the CG meetings to show appreciation of what he had learnt from the workshop	1 hr	Although this was the first interview with SS16 and he was new to the CG, the rapport was good and he was very interested in revealing his views and opinions
SS17	F			✓	Attended the workshop on behalf of palliative care and was also new to the group	40 mins	This was a first interview with SS17 and was a very difficult interview. SS17 appeared nervous and reluctant to answer some of the questions
SS18	F	✓ (SHA)			Various cancer informants recommended SS18. It was important to gain her impressions of health economics, to find out whether health economics was being used more at the SHA than at the PCT level	40 mins	This interview was very relaxed and friendly. It was held at one of the boardrooms of the hospital

Table 3C: economists' backgrounds and interview descriptions

Code	Sex	Experience			Reason for interviewing	Time	Comments on interview
		Local	*Academia*	*National (N) or Priority Setting Forum (P)*			
E1	F		✓	✓ (N)	Interest in public health and involvement in national decision-making body	30 minutes	As the first interview, it immediately became apparent that was difficult to conduct telephone interviews because not face-to-face and rapport not previously established. Interviewer was slightly intimated by seniority of health economist. However, informant spoke freely and in detail
E2	M		✓	✓ (N)	Involvement in national decision-making body	30 minutes	Interviewer was nervous at the beginning as reflected by sharp answers. Rapport improved towards the end of the interview
E3	M	✓	✓	✓ (N)	Involvement in national decision-making body and experience of local decision-making	45 mins	It was a very difficult interview because the interviewee was questioning the questions put to him
E4	M		✓	✓ (P)	Interest in methodological developments in health economics	30 mins	Very good rapport and ease of responses
E5	M		✓	✓ (N)	Concern with using economic frameworks in decision-making	45 mins	Very good rapport and ease of responses

E6	M	✓	✓		Replied to health economics circular regarding how to help decision makers with using health economics at the local level (when forming ideas about the workshop). Experience of local decision-making	30 mins	Excellent rapport and ease of responses. Had established rapport through previous e-mails
E7	M		✓		Concern with using economic frameworks in decision-making and interested in use of economic evaluations in decision-making	20 mins	Very good rapport and ease of responses
E8	M			✓ (N)	Replied to health economics circular regarding how to help decision makers with using health economics at the local level (when forming ideas about the workshop)	40 mins	Excellent rapport and ease of responses
E9	M		✓		Recommended by E8	30 mins	Very good rapport and ease of responses
E10	M	✓			Recommended by E6. Experience of local decision-making	30 mins	Very good rapport and ease of responses. Audio recorder failed to work properly during interview
E11	F	✓		✓ (P)	Recommended by E7 and was concerned with using economic frameworks in decision-making	45 mins	Very good rapport and ease of responses. Audio recorder failed to work properly during interview
E12	M		✓	✓ (N)	Involvement in national decision-making body	40 mins	Very good rapport and ease of responses

E13	F	✓		✓ (N – but primarily local decision-making)	Recommended by E6 and experience of local decision-making	35 mins	Very good rapport and ease of responses
E14	F	✓			Recommended by E6 and experience of local decision-making	30 mins	Very good rapport and ease of responses
E15	M		✓	✓ (P)	Member of priority setting forum	25 mins	Very good rapport and ease of responses

Chapter 4: "It is all fire fighting": context for local decision-making

This chapter explores local health care decision-making, according to the views and opinions of informants, providing a contextual basis for the findings in Chapter 5. This chapter comprises two main sections. The first section explores the formal structure and process of decision-making, in relation to three foci: formal decision-making; the organisational context of decision-making; and the process of decision-making. Findings in the second section, however, reveal a more complex and less transparent system in comparison to formal decision-making, suggesting pluralistic bargaining, in which individual rationalities are shaped by personal incentives and motivations. The final section of this chapter provides a brief conclusion and possible implications of these findings.

Throughout the following chapters, distinctions in views and opinions are frequently made between PCT informants (those informants who were senior managers at the PCT and not members of the CG) and CG informants (who were interviewed in their capacity in the CG; although S2 and S5 were also senior members of the PCT). Such sharp contrasts in views and opinions were particularly evident during the CG meetings, but further shown in interviews with informants.

On a final note, throughout this thesis, no detailed reference has been made to the health organisation's financial situation or the population covered, in order to retain confidentiality. It can be noted here, however, that the PCT faced a budget deficit throughout the period of the research. In addition, the area covered an average population typical for a PCT (about one hundred thousand people).

1. Formal decision-making

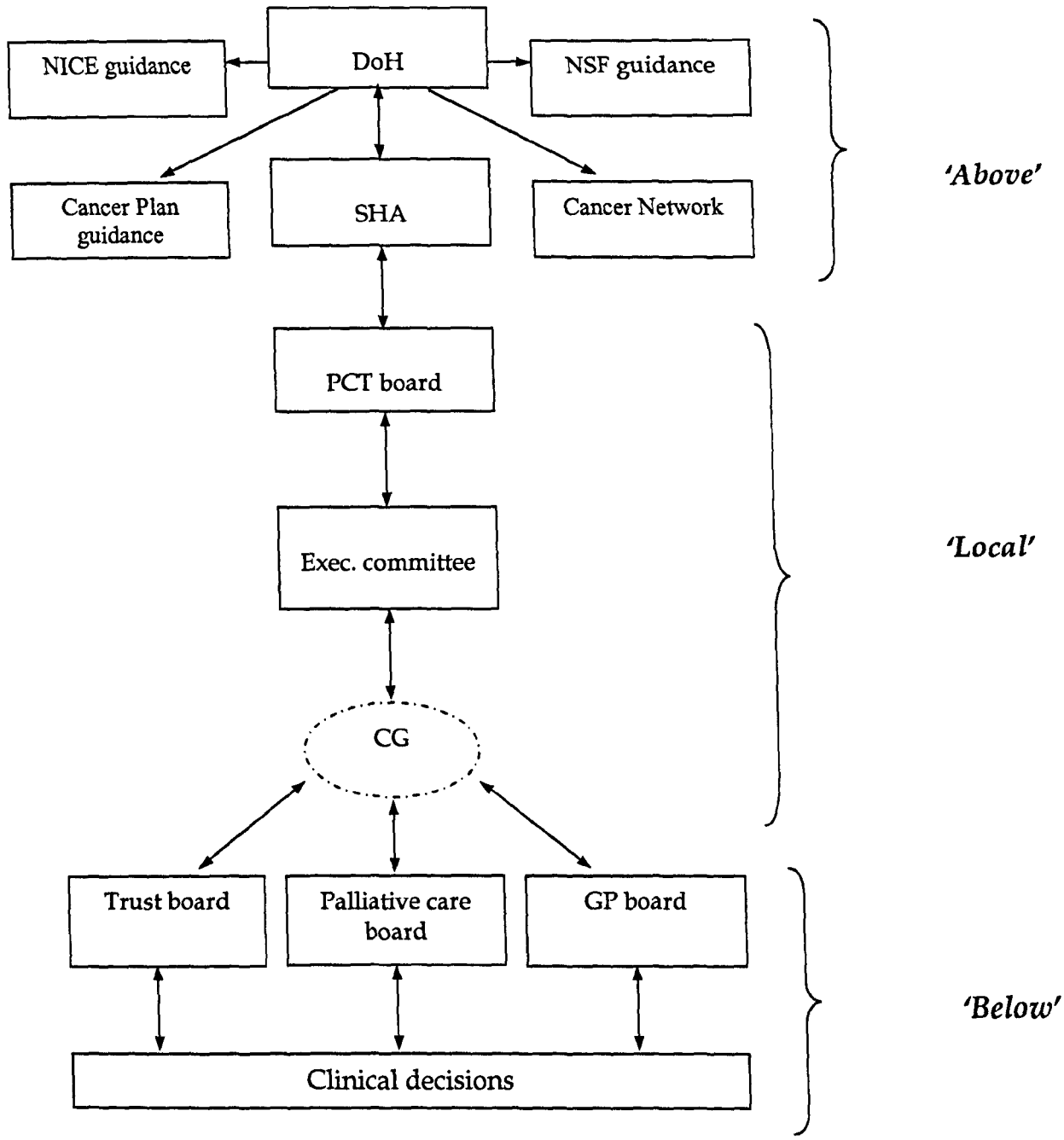
The first half of this chapter explores the formal and explicit decision-making which was assumed by those interviewed at more senior PCT levels. Here, the focus is on the perceived structure of decision-making, and organisational factors, mainly in relation to national policy. The process of decision-making discussed towards the end of this part of the chapter involved a relatively clear basis and discrete decisions being made within a formal setting (the PCT and/or CG).

1.1 The formal structure

The formal structure of decision-making is shown in Figure 4.1. This diagrammatic representation of decision-making was developed over time by the researcher, continually modified and revised through ideas obtained from observing decision makers in their natural setting and confirming/disconfirming ideas in interviews with decision makers. Thus, Figure 4.1 represents the final representation of decision-making derived from this long, but fruitful process of trying to understand how decisions are arrived at locally.

As is suggested by Figure 4.1, the majority of informants perceived the organisation of health care delivery to be "bureaucratic" or "hierarchical". However, there also appeared to be a network model in place. Although there were three levels of decision-making, different layers comprised the levels. For instance, 'below' the PCT level, the CG represented a formal layer of decision-making joining different decision makers together. Clinicians were also part of this level. Decisions fed up and down this process, as represented by the two directional flow arrows. It is difficult to assess from Figure 4.1 where in the organisation decisions are actually made (this issue is discussed later in the chapter). The point of the researchers 'entry' into the decision-making process was the CG (hence shown as a dotted circle in the figure).

Figure 4.1: formal structure of decision-making for cancer services[xi]



The three levels of decision-making and their corresponding layers are discussed as follows.

a) The 'local level': PCT board and executive committee

There was consensus among informants that the PCT (consisting of the PCT board and executive committee, a sub-committee or advisory group to the

[xi] Information feeding from above and below was found to be typical for decision-making in any disease/treatment area, although the nature of the information would most likely vary for different programme areas (for instance, the Network is specific to cancer).

board of the PCT) was the main decision-making body. PCT board meetings were held bi-monthly, usually attended by the chief executive, the director of public health, chair of the PCT, director of finance, clinicians, and nurses. In addition to these members, the executive committee also included representatives from the public. Informants believed that PCTs were the main decision-making bodies in health care, largely because they were primary budget holders:

> *S3: ...The commissioners are the people who make the decisions. We have to help inform the decision-making, but the PCTs are the commissioners and they commission health care, they are the ones with the money and they decide how they are going to spend it and that is the decision-making forum... It's got to be the PCTs who make the final decision, because they are the ones with the purse strings, and if the MRI[xii] scanner is going to cost more money than we currently have for providing the current scanner, they have to give it to us and if they ain't got it, they're not going to give it to us.*

> *S8: I think ultimately the decision makers are the commissioners. Ultimately in terms of where money gets spent, where money gets provided to deliver services, it's the commissioners and it's primary care.*

Informants agreed that the PCT monitored the behaviour of local providers and ensured adherence to targets. In addition to these roles, PCT informants felt that some assessment of what was being provided was a necessary role for the PCT, and this involved efficiency appraisal (in terms of "what we expect to be getting for the money we are putting in"):

> *S12:...Looking at what we are commissioning from the [Trusts], what we're planning to do in terms of commissioning intermediate care so some level of control. And then we should be monitoring whether or not those decisions on commissioning [are achieved] and what we expect to be getting for the money we are putting in is delivered and ensure we are actually online with regards to both operational targets, and for example on access, and also we are achieving those within the financial envelope we have available to us.*

[xii] Magnetic Resonance Imaging (MRI) is an imaging modality, which provides a view inside the human body. It is used for the diagnosis of many types of injuries and conditions including cancer.

This suggests, as also proposed in chapter 1, that the PCT does have a strategic role and its control of the budget would make it more likely to address efficiency issues. In this study, the PCT was responsible for ratifying decisions made across all programme areas before they were submitted to the SHA for final approval. Approved programmes were then included in the LDP, which detailed local investments planned over a three-year period. The LDP, for 2004-2008, concerned two main areas: service development and financial planning. Apart from the obvious need to meet the targets (in the five clinical areas mentioned in chapter 1), which was the main focus of the LDP, service development encompassed the delivery of health care as a whole, categorised into four areas. Firstly, it included designing services around the whole patient pathway of care, which meant that it was not just limited to an organisation. Secondly, the LDP included planned development of accessible services in the locality, through out of hour's primary care teams and outpatient services supplied by a hospital doctor or specialist GP. Thirdly, the provision of high quality and accessible emergency care was proposed. Finally, access to tertiary care was also deemed appropriate for improvement. Most of the areas related to achieving national policy, in terms of strengthening the patient pathway (as specified in national rhetoric) and access targets. Financial planning was also subject to national measures, such as national target efficiency savings.

Although the PCT appeared to have a clear strategy, its decision-making cannot be seen in isolation, being influenced from below and above.

Influences from below

Influences from below included the CG, groups feeding into the CG (the Trust board, palliative care board, and GP board) and decisions made on a day-to-day basis by both clinicians and managers at the local level.

CG

The CG fed their recommendations into the PCT board and executive committee. The CG was an important facet of PCT decision-making since it brought together the relevant stakeholders (individuals in purely management roles and those in direct contact with patients) to discuss important issues about the funding of cancer services and treatments. These decisions were to inform PCT final decision-making. Several informants suggested that there was a two-way process between the PCT and the CG (again, as reflected in Figure 4.1 by the two directional flow arrows):

> *S2:...Originally [decisions] will be made within a small group and then the decision which was made within a small group will go to the larger group, the committee, where it will be informed and discussed and the decision made, which will then be fed up to the board. The decision by the board will then be fed back to the committee, the site specialist group, or whatever group, so it's a two-way process.*

Informants felt that the CG provided a way of uniting all relevant providers and commissioners of care to discuss cancer care. This might explain why the CG was termed a "hub and spokes model" by several informants, suggesting a network of health care delivery, with a clear focus of control. The hub was the PCT, which was attached to spokes, or local services in the community (mainly GP and hospital services). These groups had links with each other in the local community. PCT informants in particular suggested that co-operation was necessary between members of the CG, in order to facilitate a "partnership" working. They felt that, on the whole, this was being achieved with some success:

> *S12:...Theory is they should be coming together saying, "Right this is the model of service we want to have, we need to spend on that, we need to stop spending on that, and this is how we are going to monitor what is going on", therefore that's real partnership working whereas in the past perhaps...you'd have a bidding process where the Trust would come in and say, "We'll have another MRI scanner" or "I want to have this or that" and primary care would say it would want something and someone would make the decisions, so the fact that we are working much more across a whole pathway...*

Most informants felt that the PCT was responsible for evaluating methods of delivering services appropriately, by *rationing* care, which involved making disinvestments where appropriate and setting priorities (although, interestingly, from observing the CG, it appeared that disinvestments or priority setting did not take place - this is further discussed in chapter 5):

> *S12:...[Groups such as the CG have to] look at what key targets they have to achieve, look at what resources they're using, and also then try and ensure that they stop doing those things that aren't effective, and say how best they can deliver those resources, so working across health and social care together with patient and user input, community input.*

> *S13:...The danger is what then happens is that accountants and non-clinicians potentially make priorities which is not right, so we pushed it back to say that, "Well we can't tell what's going to be available for cancer or CHD because it just depends on what the big picture looks like, but what we want you to do is give us a one to ten priority..."*

According to S12, rationing inevitably involved a larger group of decision makers than those attending the CG, including, for instance, social care workers, patients, user groups, and the community (typically through PCT board meetings which were open to the public). This again suggests a network model of organisation, with responsibility for rationing care being diffused among different individuals.

Groups feeding into the CG

Informants suggested that providers of care were responsible for assessing their own local needs and subsequent priorities. Option appraisal was being used by the Trust to formally request funding from the PCT. Apart from requiring formal PCT approval, option appraisal required endorsement from various authorities within the Trust, such as the surgical board and management board. Although option appraisals were not used in primary (GP) or palliative care, they convened their own meeting groups to decide local needs and funding requirements related to cancer care.

Clinical decisions

Decisions were made on a day-to-day basis by clinicians and managers. Some of these decisions were made in response to new and emerging problems, rather than in relation to previous policies or decisions. In this sense, often there was not enough information to be able to reach a decision. This inevitably meant that the process of decision-making was affected:

> *S3: ...More often than not...there are things that people ask you to make decisions about or on and you don't have sufficient information to hand...What I tend to do in those sort of situations is ask that person to provide me with a very small briefing in terms of give me a bit more history, give me a bit more information...What I normally do is pick up the phone and speak to the appropriate individual, and usually it's a clinical issue.*

There appeared to be a degree of autonomy among clinicians and managers to use their best judgement for these decisions. For instance, S3 said that she would often consult clinicians in order to reach a decision. Indeed, key decision makers (the chair and chief executive of the PCT, as well as the public health director) supported decisions regarding resource allocation or rationing care being made by clinicians, or those closer to the patient:

> *S12:...We are trying to get decisions made where they are best made, which is generally closer to the patient. Providing they are made within protocols and people are in power. So people should be in power to make decisions and clinicians should be making most of those key decisions and clinicians should actually be advising us very much on allocation of resources within service areas and overall within the context of having to deliver on the targets...*

Again, such comments pointed to a two-way process of decision-making, where clinicians were able to influence decisions made by groups such as the CG, and ultimately the PCT. Clinicians are clearly as important a group of decision makers as the PCT.

Influences from above

Groups influencing the PCT from above included the Cancer Network and SHA.

Network

The Network operated within a local geographical area comprising several PCTs, Trusts, and hospices. According to one informant (S19), the effective powers of the Network had diminished over time. In the past, the Network had led a decision-making body whose membership consisted of chief executives from HAs and Trusts. The Network's current role was restricted to facilitating rather than actual decision-making between relevant groups at the local level:

> *S20: We are just facilitators for the groups [such as cancer], we have no power whatsoever. We just try and get everyone together to talk and to move them along for a decision to be made, or if they can't make a decision, to find out reasons why they can't make a decision, why they are disagreeing, and then maybe to facilitate process between clinicians, or between managers or clinicians.*

> *S3:...They are not a group that has any real powers because...they are a virtual organisation...*

It appeared that the Network had a more general role, involving ensuring adequate provision of services across a wide geographical area and encouraging local implementation of national targets:

> *S19:...We are pulling a lot of information, not looking at one particular service, we're looking at it across. How does not doing this affect other Trusts, other patients within the area?...*

> *SS9:...The network are trying to influence the SHA...It's influencing the hospital and the SHA, because the network's role is to implement what the Department of Health are saying in terms of quality and guidance...*

There was a two-way process between the Network and decision-making groups or individuals at the local level, particularly in trying to meet the targets:

S19:...What we try and do is get decision-making from the ground and feed it through a process up to the people that will pay, and back to the DoH for the targets, and it is a constant flow, so we get these are the targets, this is what we want you to do, Department of Health, SHA, PCTs, and ourselves, back down to the floor, where the Trusts and the GPs are doing their job, so it's a flow, they have got a requirement and it's about how you meet it.

SHA

Informants believed that the SHA were responsible for monitoring the PCT, performance managing local providers and commissioners to ensure compliance with national requirements, setting the overall level of finance, and assessing the needs of the local population:

S2:...The SHA, amongst other things, monitors [us]. So every now and then, it will ask us, "Have you got a simulator? Are you managing to see all patients referred to you, or referred to the hospital sector, inside a month?"...But the other thing that it does is performance manages, it also sets the envelope...so when we are all confused and arguing with each other about whether there is or there isn't money, or who is going to make the savings, or what's the size of the deficit, at the end of the day, the SHA will say, "Stop, stop arguing, this is the way it is"...

S18:... It's working with each organisation to say, "OK, the financial envelope in which you are working, these are the constraints that you've got, this is the system that you're working in, how are you going to plan to reach that target?" But also, it is about...local priorities, to make sure that while they are looking at national priorities, they are also looking at the needs of their local population...

The SHA's main role was to ensure that the PCT and Trusts complied with the targets. They were also responsible for approving the total amount of money secured for each programme area, such as cancer. One informant (S13), however, suggested there was limited scope for the SHA in actual local decision-making, implying a less hierarchical structure than might be assumed:

S13:...The SHA, do they have a significant role in determining local policy? I am not actually convinced that they do. Their role is very much monitoring, how we are implementing and delivering national performance service, clinical objectives...

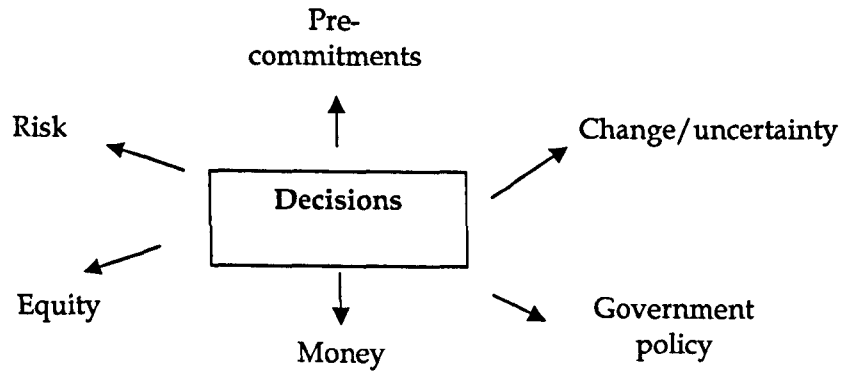
This is unsurprising, given that the SHA were not directly involved in local policy, but were advised by the PCT and were less connected to groups such as the CG.

1.2 Organisational context of decision-making

All informants discussed the organisational context of decision-making, or external pressures on the organisation as a whole, which had implications for decision-making. The organisational context of decision-making was characterised by three factors: the need to comply with national directives; lack of financial resources; and organisational, personnel, and financial uncertainty. The need to comply with national directives is discussed in section 1.3, rather than here, since clear links are made between the process and the directives when examining specific case studies of decision-making.

This section examines the influences on decisions that were made by the CG (shown in Figure 4.2).

Figure 4.2: conceptual model of influences on decisions



These factors which influence the CG's decisions are discussed in relation to the organisational context of decision-making and the process of decision-making, before moving on to examine how individual's behaviour and

perceptions influences the process (in informal decision-making in section 2 of this chapter).

a) Lack of money: "we are scrambling to fit within the resources"

All informants perceived limited local funds, which meant that decisions were driven by what was financially affordable. Most informants felt that this had implications for the priorities which were made:

> *S1: Actually the final decision tends to revolve around what we can financially afford.*
>
> *S2: I have to say in the end, we are scrambling to fit within the resources we have got at the moment, and that is the dominant feature.*
>
> *S10: The NHS is extremely under-funded. As a result it means that decisions are very cost driven really and priorities are made on the basis of how much money you've got.*

Most informants suggested that the main reason for the financial problems was because of the need to allocate a substantial proportion of local funds to meeting national priorities. The situation appeared to be exacerbated by the high cost of retaining staff in the area.

b) Change and uncertainty: "a huge pressure"

Almost all informants suggested that constant change or uncertainty was a huge pressure. These concerned organisational, personnel, and financial change or uncertainty.

Organisational change: "feeding the beast"

Around a third of informants felt that organisational change, largely associated with the devolution of PCTs from HAs, was an important characteristic of the context of decision-making. The devolution was seen as

disruptive, causing unnecessary bureaucracy and difficulties in coping with the now smaller organisations:

> *S12: PCTs don't have the same management depth and therefore capacity as the former Health Authorities, because the former Health Authorities split up, so they are a huge pressure.*

> *S13: We have got so many small statutory organisations now: we have [X] times the number of statutory organisations that existed 3 years ago, they are too small and you spend so much time feeding the beast and doing statutory reporting.*

> *S10: The Government brought in PCTs and ... before at a Health Authority level, decision-making used to be a lot more effective...You've now got [X] PCTs where you had one Health Authority and so you've doubled everything by [X]...*

One informant (S6) was particularly sceptical about the motivations behind the recent organisational change. He felt that the Government were continually trying to change the organisational structure of the NHS because none of the organisational models had worked so far:

> *S6: The NHS is in constant change, constant flux, because there are one or two absolutes in the NHS, and that is that the previous model didn't work, the current model is causing different problems, and they are now looking at a different model. And anywhere in the last thirty years we have been at this stage...The rate at which they change those is now just speeded up, so new models have come through at a much faster rate, which has appeared to be quite disruptive really.*

Personnel change: "turnover of management"

Around a fifth of informants regarded a high turnover of staff in the PCT and Trust as exacerbating the organisational instability. Some suggested that either management staff was reluctant to stay or was forced to leave, as a consequence of financial deficits:

> *S6: Every year there's at least two changes in the personnel from the PCTs. There has never been a period in which the personnel that we are dealing with has remained the same. They're always constantly changing, that's a feature of the NHS management...*

S12:...There has been substantial turnover of management in the last few years and that always makes change much more difficult because there isn't a constant management with clear direction and purpose. If you have many changes in terms of chief executives or finance directors, or of directors of human resources, it's much, much more difficult to get stability sufficient to manage a very significant change programme.

This uncertainty about the duration for which staff would be in post appeared to be disruptive and created feelings of instability among a range of informants from different backgrounds.

Financial uncertainty: "no idea of what level of funding you are actually aiming at"

Several informants, including the chair of the CG, felt that the quantity of financial resources available to cancer care was uncertain and there was not a fixed budget that they could work within. None of the informants seemed to be able to explain why this was the case, although there were urgent and unforeseen expenditures, which might have contributed to this perspective. Indeed, there appeared to be an element of fatalism, with some informants feeling that they just did not know how much funding was available and, further, that there was no possibility of finding this information.

One informant, however, claimed that the financial uncertainty was a deliberate ploy by the Government to exert control over the local level by making them feel unsettled:

S6: It's all because the way the Department of Health works. To keep people from being too settled and questioning and getting stuck into things, you just constantly unsettle them. And the way to that is to have constant change so you reorganise them all the time, you move them around but also when you do give them money you give them money at very short notice with only a week or two to create an application for it...

Several informants suggested that financial uncertainty rendered it difficult to set priorities, or to develop a long-term strategy. Instead, the focus was on the attainment of short-term goals:

S6: No idea of what level of funding you are actually aiming at and that actually cripples your decision-making because you can't grasp and say, "Yes right, that's the money we've got, how do we put that to best use?"

Two hospital informants (S8, S9) claimed that since they were not aware of how much money was allocated to cancer care, they tended to submit all requests for funding to the CG in the hope that some would be accepted.

1.3. *Process of decision-making*

Inevitably, both the formal structure and organisational context of decision-making had strong implications for the process of decision-making, although, these factors do not fully capture the pressures from below the PCT. For clarification purposes, the process of decision-making surrounding several decisions that passed through the CG is shown in Table 4A at the end of this chapter. During the process, pressures from above were largely in relation to national directives, such as the targets and NICE requirements. Pressures from below the PCT included the need to provide a safe service within the Trust, distribute care equitably, and follow through any "pre-commitments" or decisions made previously. Pressures from above and below are discussed in turn.

a) Pressures from above: "priority has to go to attaining targets"

National directives[xiii] were seen to constrain local decision-making because they were not regarded as local priorities but their implementation required additional financial resources, which, as discussed previously, were lacking.

[xiii] National wait time targets are detailed in chapter 1. National directives also include implementing national screening policies and NICE guidance.

Affordability: "what I disagree is that it doesn't come with any funding"

The vast majority of informants agreed that national directives were not affordable, as there was no funding provided by the Government to implement them. This was particularly in relation to recommendations from NICE. Following NICE recommendations was the largest item of expenditure, constituting more than 60% of the financial burden of all programmes in the locality. The burden from NICE recommendations was typically associated with NICE drugs. There were four cancer drugs newly recommended by NICE ("NICE drugs"[xiv]) during the period of fieldwork. These drugs are presented in Table 4B at the end of this chapter. The chair of the CG estimated that implementing NICE drugs would cost the PCT around £600,000 over a three-year period, largely because of the necessary additional services or staff that were required to monitor use of the drugs (such as additional nurses or specialist equipment).

Apart from NICE drugs, national screening directives presented a huge financial pressure. Implementing the national directive to extend the age range for breast screening women from 50-64 year olds to 50-70 year olds would require additional capacity with an estimated cost in excess of £200,000, although this was only one-third of that needed for implementation of NICE recommendations. However, the majority of CG informants were frustrated about the affordability of national guidance, and they vented this frustration both privately and publicly. They felt that implementing national policies meant that other local priorities were forgone.

The financial issue associated with implementation of NICE drugs further created concern among some decision makers, about how to handle the denial of NICE drugs to patients because the PCT could not afford them:

[xiv] NICE drugs was a term used by informants to refer to drugs that NICE had approved.

S3:...If NICE suddenly announce today there's a new drug and you can use it for them tomorrow and that we have 400 patients clamouring at the door, we won't necessarily have got the money to pay for it...PCTs might say, "Well sorry but you can't implement that immediately" and if you're the doctor and the patient's sitting in front of you saying, "I read yesterday that this particular drug was available and you can give it to me now because NICE have said so" what would you do as a doctor who's sitting in front of that patient?...

The chair of the CG appeared to be oblivious to these concerns when he informed clinicians, during a CG meeting, to 'stagger' or delay the use of NICE drugs and, in some cases, resist using the drugs, if there was clinical support for such resistance. In addition, the chair was adamant that clinicians should face their responsibility for clinical decision-making, of which NICE might be one facet.

Directives "not our highest priority"

The directives were not seen as a high priority locally, since they were national guidance, which did not correspond to priorities at the local level. The majority of decisions or recommendations made by the CG were seen as being based on requirements in the Cancer Plan, guidance in the NSFs, or from NICE:

S3: The Cancer Plan gives us very clear targets to achieve certain things by certain years, and clearly all these [meeting groups such as cancer], in the main, are based round either a Cancer Plan or a NSF. So all the priorities which are being put forward for decision-making on funding are linked to targets set out in either the Cancer Plan or the NSFs. So, they are not something that we have just plucked out of the air and said, "This might just be very nice to do and this is a priority"...So to achieve this specific target the Government has set us, this is what we need to invest to do it and if we don't get the money we are not going to achieve the target.

Most decisions were made solely upon the basis of being a national requirement [NICE drugs, breast screening, cervical screening, MRI scanning, endoscopy, Computerised Topography (CT) scanning, and Positron Emission

Topography (PET)[xv] scanning]. With regard to the MRI scanner, SS9 explained how some decisions might not appear, on the surface, to be related to a national directive, but were in practice:

> *SS9:...A replacement MRI scanner, on the surface that doesn't seem as though it helps us with targets, but it helps us in attaining the 2-week target and also the 62-day target...Diagnostics is one of the biggest bottlenecks that we have got here for MRI so by increasing the capacity, we should then be able to see patients in a timely fashion. Sometimes on the surface...we must attain the 31 target for x and this is what we need to put in place is actually something else which is removing a bottleneck from the process in order to attain the target...*

Most informants felt that national directives were not local priorities, although they clearly affected the policy of the PCT:

> *S11: ...My job is to deliver Government policy, that's what I see my job as. But...about two years ago I would have said, "My job is to deliver the best possible services to the local population". And the two statements are equally true, but depending on which day you catch me on I'll describe it differently, because it depends on whether I've been focusing on the latest things we've got to deliver or whether I've been out talking to the public.*

This suggests that dealing with national directives was not necessarily optimal for the local population. CG informants also agreed that PET and CT scanners were needed to comply with the national targets, but were not a local priority. Hence, most informants felt that more local decision-making would be appropriate:

> *SS4: ...If we're really trying to do what's best for the local people, it may not necessarily be one of those Government targets, but one of the other issues that we should be concentrating on...*

Apart from national directives not corresponding well to the local level, there was also an argument among some informants against the clinical benefits of following some of the national policies. Some informants with clinical

[xv] This is a diagnostic examination that develops views inside the human body, which is then used to evaluate a variety of diseases.

backgrounds felt that the targets excluded those who did not have (or were not suspected of having) cancer but were in equal need of treatment. This implied that the targets did not address local need:

> *S1: The two-week wait for cancer is disproportionate to the service we are providing in other specialties. It is quite unacceptable that people should wait for two or three years for a knee replacement when they are crippled; meanwhile someone is getting in the next week because they happen to have cancer...*

> *S10: Most people that are on a waiting list for cataracts have got very small cataracts and they expect to wait a year and a half so they all go on the waiting list quite early anyway, but you've got loads of people who are waiting for exercise tests who...are still having to wait years...*

> *S4:...There are patients with severe lung disease, which is non-malignant, who would benefit from being seen urgently...*

Furthermore, it was the view of these informants that tight treatment timelines may not offer substantial clinical benefits to cancer patients and that focusing on wait times could adversely affect clinical quality:

> *S6: Everyone thinks targets are a good thing but when the [hospital missed some of] its targets...it still rated very highly on its clinical side...But the detrimental effect here is that if you are trying to be good clinically, i.e. you want to concentrate on people's health or their illness, you automatically cannot fulfil Governments targets...you can't do the two. It's the perverse nature of things.*

S4 objected to using some NICE drugs based on his clinical experience. He felt that NICE drugs were not necessarily any more clinically effective than current practice and although some NICE drugs could prolong survival, often they were not associated with any improvement in quality of life because of side effects of the drugs. He felt that there were other drugs which NICE had not considered and which would be more beneficial to his patients. In

addition, SS1 suggested that cervical cytology screening[xvi], which was a mandate from the Government, was not a local priority at all:

> *SS1:...Cervical cytology screening, which is a national thing, it's a must do, it's going to cost half a million pounds. I think we're agreed as a group that's not our highest priority and we wouldn't spend half a million pounds on that. If someone came to us with a bag full of money, then we would not be spending it on cervical cytology, but we have to.*

SS1 stated that even if the CG had sufficient funds, they would not choose to implement cervical cytology screening, suggesting that it was not just lack of money which meant it was not a priority but also clinical factors. He felt there were higher priorities, such as addressing waiting times for radiotherapy, providing computer aided oncology prescribing, and implementing community based chemotherapy.

However, there were strong incentives to follow national policy. With regard to NICE drugs, the majority of informants' felt that they were unable to "disobey" the recommendations:

> *S3:... They are not going to have a huge amount of option on NICE, because NICE is practically statutory, so when NICE recommends something, PCTs do not have the ability to opt out and not fund...*

Although there were insufficient funds to implement NICE drugs, there was a strong incentive for providers to prescribe the drugs. According to S1, most GPs in his area were fearful of being taken to court by patients who had not received NICE drugs. Additionally, the chair of the CG mentioned that one area had tried to restrict use of NICE drugs and consequently the chief executive of the PCT was almost dismissed from his position. In addition, for PCT informants, there appeared to be no alternative but to follow the targets because of the fear of losing their jobs:

[xvi] Cervical cytology is a liquid based technology designed to reduce the rate of clinically unsatisfactory smears, and hence the need for repeat smears.

S11: The NHS is becoming incredibly ruthless... We've lost chief executives left, right and centre; the chief executives in this patch who are looking over their shoulder as to whether or not they have a job.

S12:...I don't think that a chair of a board or a chief executive could expect to be continuing in their roles [if they missed the targets]. They'd get the sack.

In summary, although there was clear priority setting (and the word priority was spontaneously used by a range of informants), there was limited local discretion for considering local objectives and most decisions were nationally driven. This implies that non-(local) decision-making might be a feature of the NHS. At the same time, there were pressures from below for local priority setting, although these tended to be overshadowed by national directives.

b) Pressures from below: local basis for decision-making

Although the majority of decisions were associated with national directives, which had a clear national basis, there were also acknowledged local criteria for decision-making, including the desire to achieve a safe service, achieving some notion of equity locally, and implementing decisions made previously. The bases for local decisions are discussed in turn. Note that where local decisions were made, they concerned employing extra staff or retaining particular services (such as ensuring paediatric oncology services were not located elsewhere). Decisions, therefore, did not concern different types of treatment for patients or effective delivery of a particular oncology programme for instance.

Risk: "a safe service"

During interview, around a quarter of informants suggested that preventing clinical risk to patients was an important, if not the most important factor, in local decision-making:

S11:..Most decisions are about assessing the risk, "Am I going to do this or am I going to do that?"

For instance, quality of care might be adversely affected if a particular modality is not installed. Furthermore, shortages of required members of staff might create difficulties in ensuring patients are treated on time and by the correct staff:

> *SS1:... Clinical risk is the most important. If we perceive there is a serious clinical risk issue then that makes that particular requirement for development number one and that's above everything really. If something is putting patients at risk because there is a particular piece of kit that is not there, or a particular nurse that should be employed but isn't, or particular shortage of one particular modality or something and that is putting patients at risk, or indeed staff at risk...*

Two CG decisions that involved a clinical risk were shortages of oncology nurses and paediatric oncology nurses in the Trust. The request for extra funding for nurses is an important case study to reflect upon here, since option appraisal was prepared by the Trust and presented to the CG outlining the urgent and apparently unforeseen need. According to the Trust, additional oncology nurses were required mainly because of a shortage of staff and also to ensure that the standard of the oncology unit was maintained in alignment with standards set out in the Cancer Plan and NICE guidance. Other informants, who were not necessarily from the Trust, also supported this:

> *S3:...The ward nursing...was...a qualitative issue and risk management of the patients, because of having the right level of staff...*
>
> *S1: Oncology nurses...that is a safe service, it is nothing to do with targets, it is to do with the fact that we believe that the service that is being provided at the moment is actually unsafe because the pressures on the staff, work pressures they are working under and the things they are expected to do to meet the targets. It is not that they are not meeting the targets but they are doing so in a potentially unsafe way, not through any fault of their own.*
>
> *S2:...The oncology nursing situation...is really another risk assessment and we are saying we feel we have no choice but to improve the staffing levels of the oncology service otherwise we would have to stop the service, it would be that extreme and serious.*

However, it is interesting to note that there was no reflection as to why this urgent situation had occurred, what had led to the problem, and what other options might be in place to remedy it, other than to employ more staff. Furthermore, the option to withdraw a service was deemed impossible and informants appeared to use emotional arguments to justify the decision (comments along the lines of 'we can't leave patients without appropriate care' were made). Similarly, with regard to paediatric oncology nurses, CG informants agreed that the inadequate medical cover in the ward represented a clinical risk to children and additional staff was absolutely necessary because otherwise the unit would have to be closed and paediatric specialities located elsewhere. The latter option was not deemed possible (because it would mean that the service might be too far for patients to reach) and was therefore never discussed. The oncology nursing case study suggests that although clinical risk was a major factor in CG decision-making, it was not clear how this was actually being assessed and the risk of alternative options was not evaluated.

Equity

Concerns about equitable care (or care reaching as many people as possible) were raised by over half the informants, particularly those in clinical roles. Where equity concerns were raised most, they were in relation to NICE drugs. For instance, two informants (S3, S6) questioned the basis of NICE drugs, feeling that local equity was not being contemplated by NICE:

> *S6: Although there is enormous pressure for say NICE drugs, if the local jigsaw picture says, "Look sod NICE drugs, that's an enormous amount of money benefiting a very small number of people, what we need is to put that money to benefit ten times that amount with these things. You NICE drugs can come in if we've still got money after all that"...*

There were also concerns raised about access to care. Two informants (SS6, SS2) felt that closing the paediatric unit would cause inequities, since an alternative unit in another area would be too distant for many families to

reach. GPs in particular felt that it was important for patients to receive the same access to care:

> *S10: Everyone should have the same sort of level of care and deserve the same access to health care.*

This would mean, for example, that all patients are able to access the Trust (which might involve ensuring that there is sufficient parking space available) and receive nursing at home if they needed it. There should be no difference in the level of care between patients undergoing the same procedure. At the same time, achieving equity locally was not desirable in all cases, as S10 was strongly opposed to Government initiatives, which proposed that all GP practices should offer the same services. He felt that this would bring everyone down to the "lowest common denominator" and restrict the type of services offered. This suggests he was willing to trade equity for other perceived values such as increasing the total benefits or increasing the range of choice available to patients.

Pre-commitments: "wedded to buildings and beds"

Several informants believed that some decisions made by the CG were the result of previous decisions or policies, which they were not responsible for but which could not be changed. For example, for one decision concerning investment in a CT scanner, informants agreed that it was pointless not to use a piece of equipment that was already physically in the Trust and thus violate a purchasing agreement, for which the Trust could be penalised. However, purchasing of the CT scanner was not a decision that the CG made, nor did it appear to have been one they would have been likely to have made. This highlighted the limited potential for decision-making where decisions were perceived as being unalterable. At a more general level, one informant (S13) described this situation as:

> *S13:...The problem that you get is that money is being invested in a particular way for many years, actually disinvesting and changing it is very hard, not*

for the want of not wanting to do it...You'd have to have different infrastructure and the problem...we are wedded to buildings and beds...actually the reality of trying to change that in a system that has already got this infrastructure that their community is already wedded to is very difficult.

This reflects the nature of health care decision-making, in that service provision is capital intensive, in terms of buildings, beds, and equipment. Indeed, S1 described the Trust as a "higgledy piggledy mess" and felt that many of the decisions by the CG would involve improving services provided by the Trust in an old and dilapidated building.

So far, formal or explicit decision-making has been explored, with the focus on the organisation as a whole, but this focus on the organisational structure, context, and process gives little insight into actual *behaviour* among decision makers. The next section explores informal decision-making, or how individual behaviour influences the process of decision-making, as this was found to be an important element of decision-making.

2. Informal decision-making

Formally, on the surface, there is a relatively clear (mainly national) basis for decision-making and also a clear structure of decision-making. It is assumed by the majority of PCT informants that the formal process of decision-making works well: a) the PCT is the final decision maker and; b) the two-way process between the PCT and CG is achieved. The focus of PCT informants was mainly on the organisational context of decision-making and the actual process in terms of how individuals make decisions was assumed to be adequate. In contrast, informal (or less transparent) decision-making revealed by the CG, exposed a far more complex system, where there were many different actors in the process, whose rationalities were shaped by personal incentives and motivations, rather than purely organisational concerns. There was not one decision maker, the PCT was not the final decision maker, and the two-way process was not working particularly well.

This informal decision-making was not something that PCT informants were aware of, or at least wanted to discuss during interview. The informal process was revealed by examining and recording individuals' behaviour during the CG meetings and their views and opinions during interview. Interestingly, CG informants were often unaware of the implicit nature of their decision-making.

The nature of the CG meetings illustrates well this informal process. In practice, the CG meetings were quite chaotic. Although an agenda was distributed to members in advance of the meeting, it was possible to deviate from this agenda (for instance where clinicians spoke about individual patients). It seemed, from comments raised during interview, that the meeting agenda was of little value in representing the real underlying issues important to the group. In some cases, the discussion was dominated by one or two individuals, so that there remained little time to discuss priorities. Often it appeared that a resolution on the decision being discussed had not been made, yet it was not brought up in future meetings, although funding seemed to have been secured. Thus, information was presented to the group without being really discussed subsequently; moreover information outside the group was not fed back in a coherent way.

This section describes the general nature of implicit decision-making in relation to five areas:

2.1 Decision-making outside the formal process

The formal process suggests that decisions are made or discussed at the CG, approval or disapproval is given by the PCT, and decisions are fed back down to lower levels of decision-making (Figure 4.1). Although there was a two-way process, the PCT was the main decision-making body. It appears however that decisions are often made prior to or subsequent to the CG meeting. This behind the scenes decision-making was much less transparent:

S10: Before we get to the [CG] meeting, most of the decisions have already been made and most of the priorities have already been set.

Here, it appeared that individual clinicians or members of the Trust were responsible for decisions made on an "informal" basis, which directly affected groups such as the CG:

S20:...There are 101 ways decisions are made in the NHS and within this network. And there are thousands and thousands of groups that get together, either socially, where work will get discussed, just like in any aspect, and then in a more formal basis, through groups to feed up to the board group.

Unlike the two-way process where the PCT was the final decision-maker, here decisions are made below the PCT. Part of the explanation for this was the inadequate formal process of decision-making that existed between the PCT and Trust:

S3:...One of the decisions I had to make just before we started was about allowing a particular type of drug to be administered tomorrow, which we are not funded for...a drug that...we won't get the money for...

In addition, it was difficult for the Trust to adhere to agreements when basic factors might change, such as the number of patients or the type of treatments available, suggesting that decisions made by the CG/PCT were often revised implicitly:

S3:...We did agree that we would implement that particular NICE drug and...we identified how many patients we thought would need it and we agreed with the PCTs that we wouldn't go above that number without talking to them about it...because we got agreement they would pay for it. The only difficulty is often you get numbers wrong...

SS4:...It's a new drug therefore it's not part of the baseline that we've been given from the PCTs...

In particular, analysis of the observation transcripts revealed that the decision-making was 'non-linear'. A case study of decision-making around

NICE drugs illustrates this point. Initially the CG agreed that it would resist funding Rituxumab (MabThera®), Imatinib (Glivec ®), Trastuzumab (Herceptin ®), and Aromatase inhibitors (see Table 4B at the end of this chapter) because there was no extra funding available in order to implement these drugs and also they felt that there were other more important local priorities. However, they had no clear strategy as to how this resistance should be achieved, and presented no written case to the PCT, instead using terminology such as "disobey" during meetings to refer to how they would respond to NICE's decisions. CG members were also aware of the potential for senior colleagues to be adversely affected by such resistance. Despite much time being discussed during meetings about not funding NICE drugs, they were eventually funded by the PCT; the chair of the CG 'told' the other members that there was no choice in this 'decision'. When asked during interview about the funding of NICE drugs, the chair simply replied that it was inevitable. Throughout subsequent meetings, members expressed their frustration about the financial situation, fuelled by the chair's reference to NICE drugs constituting one of the largest items of expenditure in the budget. Thus, decision-making surrounding NICE was not transparent because although the group thought it had made a decision not to fund NICE drugs, this decision was subsequently revoked; even then, the CG continued discussion of the topic during future meetings.

2.2 Lack of awareness of implicit basis for decision-making

PCT informants believed that most decisions should have a clear basis, considering a "rational" approach. In addition, formally, there were clear factors which the CG needed to consider, such as clinical risk. However, decision-making below the PCT was often characterised by who "shouts loudest", personal preferences, and relationships between decision makers, which did not appear to be recognised by PCT informants. For some of the decisions made, informants were aware of their implicit nature. For instance, the cancer programme had received the largest amount of funding and it was unclear as to why this had occurred:

SS8:...We have a biggest amount of investment into cancer than any other NSF or clinical area in the Trust last year and you've got to ask yourself, "Why?" Is it because [S2] is really good, is it because we were very persuasive, or was it because we had the better arguments because our needs were greater?

Similarly, GPs suggested instances where clinical decisions could be informed arbitrarily:

SS1:...We have to make what we consider to be an informed decision and sometimes the decision is somewhat arbitrary. It goes down to personal preference at the end of the day as to what we feel might be the most appropriate thing to do.

S10:...I think that probably there are some individuals that have their own little interest areas who push those within little groups and so sometimes you see things emerging [that] you just thought were a dead duck and then you realize that the GP on the PCT is best mates with the consultant urologist...

However, in other instances, it was evident that informants were not aware of their implicit decision-making. For instance, informants did not recognise that they were not making any disinvestments in cancer care despite limited funds, that they were often not making decisions because they were arguing and could not reach an agreement, and that all their priorities could not be advanced (despite some saying that they knew about scarcity and opportunity cost, as discussed in the next chapter).

2.3 *Lack of clarity about decision makers*

Figure 4.1 suggests a discrete decision-making setting and identifiable decision makers. However, as the fieldwork progressed, it was apparent that decision makers themselves were not aware of the process and who was responsible for decisions made, suggesting huge ambiguity in the system. Several informants felt that it was difficult to establish *where* and *when* decisions were made, and *who* made them. Despite being part of this local decision-making process, some informants were unable to describe the

process because they did not know how it worked (S1, S4) and others expressed hesitation in describing a system (S8, S9):

> *S3:...It is complex enough if you're working within the organisation let alone if you are looking at it from an outsider...*
>
> *OA: So [S2's] the one that's finally responsible for those decisions?*
> *SS8: I don't know*
> *OA: Because you said that he's responsible for making those decisions?*
> *SS8: Well I assume it's him, presumably he has to persuade the commissioners in the SHA, but I have no idea it works...*

Although one informant (S6) had extensive experience in local decision-making, he was unsure whether what he knew was a "real" system. Among CG informants, only two (S3, S2) could confidently express how they felt the decision-making process worked, although what they described reflected the formal process of decision-making.

Decision-making at the local level appeared to be characterised by pluralistic bargaining. The representation of the formal process in Figure 4.1 suggests the ultimate power for decision-making rests at the national level. However, the informal process points to power being a more complex issue, with medical consultants and the PCT struggling to retain authority. On the one hand, S11 felt that team based practices (suggesting a network model of decision-making) was being used:

> *S11:...There has been a lot of power around medical consultants in the past, the GP fundholding and primary care trust era is all about moving power to primary care. But whether any of that is real, it's all about moving power around. But we tend not to get the balance right...There was a debate as to who was at the pinnacle of the hierarchy, two groups like the hospital, the idea that the chief executive was in charge would be challenged by the consultants, it was always changing, changing power structures, and it is quite hierarchical but it's trying to tackle that because the model of delivering care is much more team-based now, so actually getting multidisciplinary team work going and devolve decision-making down is all part of the new culture.*

On the other hand, CG informants felt that decisions were, in practice, made by small groups of informants, even though a substantial amount of time was invested into discussion and understanding the proposals in the CG:

> *S2:...I think for the first three quarters of that time, and the whole process, it was pretty much a consensus approach, that is a lot of discussion went on, a lot trying to understand what each proposal was...I think the final quarter of the process, a much smaller group of people were involved and, if I were honest, it would be myself and one other person, a planner in this organisation, on the one hand, and another very small group of clinicians and managers at the [Trust] on the other hand.*

For final decisions made, the PCT clearly had substantial power:

> *S6:...At the end of the day [decisions] usually come down to one or two people in the PCTs.*

For example, S10 felt that even though there would be a discussion around some areas of interest, such as hospital closures, the PCT would continue with its policy at the end of the day:

> *S10:...[The CG] is just a sort of talking shop really...the Government expects there to be these groups where there's the GP and there's the consultant and there's a house wife, because they think that's how you should do things but, and so they set up all these meetings and the PCT go along with it. And so, like they are going to close down all the local hospitals in [X] and all over the place so they're going through a consultation period where loads of, hundreds of people are turning up and saying, "No way we don't want them closed down"...but they will still close down the local hospitals at the end of it.*

However, as discussed previously, there were many decisions made informally by clinicians which affected PCT policy.

2.4 *Lack of trust*

A particular problem for decision-making in the CG appeared to be the professional relationships between groups of decision makers, which are assumed to be exogenous to the formal process. PCT informants did not really discuss relationships between decision makers, although relationships

were emphasised as being important in almost all interviews with CG informants. They felt that although the CG was supposed to act as a team, this was not being achieved in practice:

> *S4: Hopefully the [CG] meeting does actually help to...provide an adequate interface between the primary and secondary care sector and improve understanding, but I am not sure that the meeting has achieved that so far.*

The main reason for team working not being fulfilled appeared to be as a result of a lack of trust between primary and secondary care. Informants regarded trust as the expectation that an individual would respond according to their role. Here, trust was in relation to an agency or advocacy role, since primary and secondary care were linked contractually to one another. Some felt that trust would only be sustained if it was reciprocal, so that all parties involved in the decision must trust each other. Trust, however, did not appear to be strong among groups involved in decision-making. There were various arguments as to why this was the case, although there appeared to be two central points, relating to lack of trust over financial issues and lack of trust in decision-making concerning referrals made by GPs. Firstly, some informants (S4, S6) felt that the PCT were abusing their budget holder position, by diverting funds to other non-agreed, and potentially questionable, projects:

> *S4:...Monies that are fed into the health service, a lot of it are being channelled through PCTs, and one wonders whether the PCTs are taking cuts off the money before passing it on. I don't know whether that is something that has any genuine truthfulness, but it's something that I am a bit concerned about. I do wonder somewhat about a lot of weird and wonderful zany projects that might have been going on out in primary care that mean that we don't finish up ever seeing the money Alan Milburn talks about.*

Similarly, S6 was concerned that many millions of pounds supposedly "ring fenced" or reserved for palliative care had been squandered by the PCT to cover their own financial deficit. On the other hand, several informants, comprising GPs and PCT managers, had a polar opposite perspective, feeling

mistrust towards secondary care's arguments for funding. Specifically, they believed that secondary care lacked the competence for priority setting, or that they treated the PCT as a "bank", being able to disperse money freely to them:

> *S6: There is no trust in decision-making from the [Trust] because we have no idea what it is that they are going for and why they've asked for this as opposed to that. I even mean that at quite a detailed level, we do not actually trust the arguments they put forward to people about some things.*

> *SS10:...They've wanted a breast surgeon, even though they don't need it but they just tend to get what they want at the end of the day...They then come to the PCT and say they want that funded.*

Secondly, some informants expressed a lack of trust in the qualitative decision-making made by GPs to refer patients to hospital. Three secondary care informants suggested that monitoring GPs' behaviour was difficult because GP practices worked fairly independently of each other. As a result, they felt that GP referrals, particularly those related to suspected cancer cases, were sometimes unreliable and did not reflect need:

> *S4: What was being found is there are a number of different ways that patients could finish up coming in through the system theoretically...There was one GP whose patient had itching, a skin rash - now itching is sometimes a feature of Hodgkin's disease, although there was no evidence of that in this particular patient's case. But the GP knew that the waiting list to get the patient seen in dermatology was in excess of 22 months but if he puts the words "suspected cancer" on the referral, then the patient gets seen within two weeks...*

> *S12: GPs feel that things need to be done, they will quite often in the end declare someone "urgent" in order to get the work done...*

Here, there was a deliberate circumvention of the formal process of decision-making.

2.5 *Personal motivations*

The basis for decision-making in the formal process largely appeared to be to achieve the targets, which were seen as compulsory, and/or maintain clinical quality. At the local level, on the surface, informants appeared to want to achieve a safe service, attain some notion of equity, and sometimes faced having to base decisions on previous decision-making or policy. By and large, different decision makers' motivations were therefore comparable. Beneath this process, however, there were other motivations, which were not related to the organisation and were more individualistic. For instance, GPs were seen as being focused on their own income. Some informants suspected that limited GP involvement in meetings was financially driven (since a GP practice would have to provide cover for an absent GP, which would incur additional costs for the practice, and would most likely affect GP income):

> *S4: GPs are regrettably, have to be, focused on their income, they can't turn up to an afternoon's meeting unless someone provides some funding...and it's very expensive...their income would suffer personally because the practice would still have to get another doctor in to see the patients. Otherwise their colleagues just finish up having to see extra patients, is that fair? You should be dividing the workload up fairly.*

For GPs SS1 and SS10, there were also incentives to generate income. SS1 referred to the temptation to record the wrong information for patients (such as blood pressure readings) because he would receive more income if able to show a reduction in patients' blood pressures:[xvii]

> *S1: There is a very easy way of making sure that your patients with hypertension have low blood pressures; you put down the wrong blood pressure. I know it sounds horrendous but you could knock a little bit off and nobody would know...and therefore some of these things are actually manipulable... it is very easy to do actually, and you can go through people and put a load of blood pressures down, you might not even see them, but you could actually put some blood pressures down to fit figures because this is going to be measured by somebody just looking at your computer.*

[xvii] As far as I was aware this practice was not going on, but was an illustration of what might happen.

This situation reflected an asymmetry of information between GPs and other decision-making bodies. Only the GP could record patient data and the commissioners or those responsible for monitoring GPs could only interpret recorded data. Again, this also reflected a situation where the clinical 'level' were affecting outcomes of policy, and, in this sense, they were far less distinct than might be assumed.

Hospital clinicians also appeared to have their own incentives. For example, there was a suggestion that the Trust were accustomed to being 'bailed out' if they exceeded their expenditure, in which case they could advance requests as they liked:

> *SS10: In the NHS, at the end of day, it is just people that sit around in a room deciding figures that everybody else completely ignores, do you see? People decide on budgets and everything else. In theory it's a good idea but in practice it doesn't work because there is no real constraint on spending. The [Trust] will spend how much it wants to spend, because at the end of the day if you were to have how much money you have to spend, you couldn't carry on spending thousands of pounds, because you'd lose your home, your car, and everything else and be declared bankrupt, and that would be it. But the hospital can carry on, it hasn't got a limit has it?*

3. Conclusion

At the formal process of decision-making that occurs at the PCT level of health care decision-making, it appears that there is a relatively clear structure, organisation, and process of decision-making. Informants were fairly unanimous in their opinions against the strong role of the Government in priority setting and there was a clear focus on organisational concerns such as NICE and the targets. However, the clarity of decision-making is strongly assumed by informants from the PCT, whose ideas are shaped by their position in the organisation. The pressures that are related to by PCT informants mainly concern organisational factors, such as the need to comply with Government targets. Among PCT informants, there is also the assumption that the CG acts as a good agent for the PCT, prioritising expenditure and informing them about where to invest or disinvest. PCT

informants felt that the network model of health care organisation was working effectively, and did not question issues of trust or partnership working. This suggests that they viewed decision-making in line with classic rationality, where there was a clear decision maker and clear decision to be made.

PCT informants seemed unaware of the pressures on groups feeding information to them, such as the CG, despite basing much of their decision-making on such information. The informal process was strongly characterised by: decision-making outside formal settings (before or after CG meetings); unawareness of implicit decision-making; lack of clarity as to where decisions are made; lack of trust; and personal motivations in decision-making, as opposed to purely organisational concerns. All together, these factors suggested that there was more of a focus on personal factors in decision-making than might be assumed, and that PCT informants were not clear about how decisions that reached them had been made and could not therefore judge whether the basis had been appropriate. At the CG level, there appeared to be a system of pluralistic bargaining, whereby individual rationalities were shaped by personal incentives and motivations (such as keeping a job and obtaining power). Decisions were made by many different actors, even before reaching the PCT, and there appeared to be an unclear basis for this. Often this created a lack of trust among decision makers, suggesting that the network model of decision-making was not working effectively in practice.

One important insight so far is that lack of trust among some decision makers and perverse incentives (for example relating to the issue of the Trust being 'bailed out') largely appear to be an internal problem among the CG. Thus, only the targets and other guidance, such as from NICE, were an external factor in decision-making, but they did not directly affect the intrinsic working of the group. Whilst decision makers appeared to spend a substantial amount of time being frustrated about national policy, they did

not recognise their own internal problems associated with, perhaps, an inability to take control of their situation. It is not clear how rational approaches such as economics would be able to cope with such chaos by enforcing a more systematic approach.

One final point should be noted from this chapter. Economists usually assume clear and distinct levels of decision-making: national, local, and clinical, each with their own set of clear and distinct decision makers. The process of local decision-making outlined here, however, includes a strong influence from national policy, but, more importantly, a much less clear distinction between local level decision-making and clinical level decision-making. Not only do the clinical actions of doctors circumvent local decisions (as in the case of referring GPs for example) but clinicians are inextricably involved in the process of local decision-making as the agents of the PCT in groups such as the CG. The following chapter investigates informants' views and opinions about use of economic evaluation in decision-making.

Table 4A: case study of decisions

Decision	Type	Basis of decision	Process of decision-making	Conflicts during the process
NICE drugs (see Table 4B)	Drugs	National decision	Debated extensively in CG, but decision eventually reached by PCT, who agreed to fund the implementation of the services and equipment required for use of the drugs	Concerns about lack of money to fund drugs, responsibility for rationing, actual (cost) effectiveness, and equity
Breast screening	Screening	National decision	Limited discussion and priority was seen as unavoidable. PCT agreed to fund additional capacity	Some private concerns, expressed during interview, as to whether breast screening was a needy clinical issue
Cervical screening	Screening	National decision	Discussed during CG but was seen as unavoidable. PCT agreed to fund additional capacity	Concerns that was not a clinical need and also very expensive
CT scanner	Equipment	Pre-commitment (also standards and targets)	Discussed during CG as a result of option appraisal. PCT agreed to fund	No opposition expressed
MRI scanner	Equipment	National targets	Discussed during CG as a result of option appraisal. Originally was not intended for allocation under cancer budget, but decision was reversed by PCT and was included in the cancer budget	No opposition expressed
PET scanning	Equipment	National decision	Discussed at CG, although no decision made	Some opposition that this was another national directive
Oncology nursing	Staff	Clinical risk (also standards and targets)	Discussed during CG as a result of option appraisal. PCT agreed to fund	No opposition expressed

Decision	Type	Basis of decision	Process of decision-making	Conflicts during the process
Paediatric oncology nursing	Staff	Clinical risk (also standards and targets)	Discussed during CG as a result of option appraisal. Assessment was undertaken to determine whether the service should be terminated. The PCT eventually decided to fund the priority	No opposition expressed
Endoscopy	Location of care	National targets	Discussed at CG but decision went outside the group	No opposition expressed
Brachytherapy	Trial	Patient choice	Discussed at CG. Since there was money from charitable sources, the PCT decided not to try to stop patients from receiving the procedure in their locality, but not to allocate any money for it	Concerns regarding cost and capacity required

Note: Option appraisals were essentially funding proposals prepared by the Trust to obtain funding from the PCTs; a national requirement refers to a wait time target (or, in the case of NICE, specific cost-effective drugs or procedures); and national standards consider clinical quality of care, usually specified in public documents (such as the Cancer Plan).

Table 4B: recommended NICE drugs for cancer

Drug	Recommendation
Rituxumab (MabThera®)	Aggressive non-Hodgkin's lymphoma
Imatinib (Glivec ®)	Chronic myeloid leukaemia
Trastuzumab (Herceptin ®)	Advanced breast cancer
Aromatase inhibitors	Early breast cancer

Chapter 5: Use of economic evaluation in decision-making: "the right way?"

The previous chapter has set the context for local decision-making, as well as the distinction between the formal and informal process which is useful for understanding the findings here. This chapter begins by examining the use of evidence in decision-making and moves on to investigate the use of technical knowledge, including economic concepts, as well as economic evaluation. It is found that whilst there is some knowledge of economic concepts, there is no use of published economic evaluation. The possible reasons for this situation are explored, followed by propositions for facilitating greater use of economic evaluation in decision-making. The chapter ends with a brief conclusion.

1. Use of evidence in decision-making

This section explores use of research evidence and non-research evidence (referred to as "learnt" evidence here), which comprises decision makers' experiences, professional beliefs, and opinions.

1.1 Research evidence: "decisions on the best possible information"

Members of the PCT were keen for the basis of decisions to be transparent and objective. This implied using formal evidence containing information about efficacy, effectiveness, and efficiency. Informants suggested that use of such evidence was associated with the PCT, CG, and clinical settings:

> *S11:...One of the big things in the NHS is about trying to force managers to make their decisions on the best possible information, analysed appropriately, as opposed to learnt experience or emotional attachments...I remember reading in a director of public health annual report once about decision-making based on value judgements that we weren't even aware of that you take to the table because you are who you are.*

> *S15:...He [a clinician] is giving you his personal advice [during CG meetings], but it doesn't necessarily represent the views of his colleagues...nor has he actually made the effort to go around and speak to them before the meeting...that's why the*

whole base of the decision must be based as much as possible on evidence...efficiency, efficacy...

Consequently, PCT informants believed that it was their role to ensure that decisions were not based on opinions or emotional attachments. The importance of making decisions on the basis of research evidence was also recognised by those in managerial positions:

SS9:...I think we have to be making the best decisions for the health community based on evidence.

S19:...Without information, you can't draw up a shopping list, you can't succinctly put in a bid and say, "And this is what we need."

The chair of the CG (S2) suggested that evidence was used about numbers needed to treat, cost to patients in terms of side effects of drugs or treatments, the financial cost, and benefits from treatment, such as the five year survival rate. Some informants claimed that they often searched for appropriate evidence on the Internet and used websites or databases, such as the Cochrane collaboration database, the British Medical Association (BMA) website, DoH and NICE websites. Such methods appeared to allow quick and easy access to relevant information for clinical decision-making:

S8: ...I am aware of the literature relating to aspects concerning cancer nursing, so some of it's published in books...just a search will lead you to various people who have written extensively on it.

S14: As a GP I could use any number of resources at my fingertips on my computer, which is really helpful. First of all there's the kind of local guidance that we might have, you could look on the BMA evidence website. A lot of practice systems have clinical support software on them; our system that we use has a thing called mentor, so if you click onto that, or you could use the British Heart Foundation website...

Where mentioned spontaneously, the evidence that was useful related to that shown in clinical papers. SS4 referred to recent cancer treatments in his field:

SS4: ...The evidence [for treating high-grade lymphoma] is...in the New England Journal of Medicine... The paper suggested that the drug reduces the relapse rate, it

increases the event free survival, and it increases the overall survival...This is a straightforward clinical paper comparing standard CHOP chemotherapy, which is what we give to people with high-grade lymphoma, CHOP with or without rituximab, and it improves it in the order of 15%, which is the first known improvement for the treatment of high-grade lymphoma in 25 years.

It appeared that once research evidence is accessed, how it is used depends on the particular context. Three PCT informants (S12, S14, S15) believed that groups such as the CG were responsible for reviewing a wide range of research evidence on particular topics, in order to reach a decision. This implies a *direct* application of research evidence, *prior* to making the decision (as in the problem-solving or knowledge-driven models of research use):

S15: [Groups such as the CG] I would have thought make decisions in an evidence-based manner. So if they had to prioritise expenditure in one area compared with expenditure in another, they may look at the evidence that underpins that and decide which provides the better health outcome.

S14: [Groups such as the CG]...take a lot of the evidence and the national guidelines and the NSFs and they kind of produce some evidence, or produce guidelines or suggested ways of delivering work. In general practice that's underpinned by the data that practice needs to provide on an annual basis, which is basically searches and audit. So you've got a clinical condition, ischaemic heart disease, you then have to identify your group of patients with that condition, so you get a disease register, you then have to implement recognised and accepted treatments for them or clinical management, you then decide who's best to deliver that...

S14 suggested that the primary care meeting group (which was a similar group to the CG, but related to issues concerning primary care) might use research evidence *directly* in deciding treatment for patients with hypercoagulation (excessive blood clotting) disorders:

S14: ...There is very good evidence that if you treat a certain group of people with a certain condition with warfarin you actually reduce the risk of them having strokes ... the numbers needed to treat is 50, so actually that's quite a low number needed to treat to prevent a condition like stroke, when you consider if you treat hypertension, you've got to treat a thousand people for about a year to prevent one stroke in the 50-60 age group. So it could make quite a dramatic impact but the number needed to harm is 300, so there is a risk with this treatment. So on one hand you've got a very effective treatment that can actually make quite a big impact on patients particularly

but also health care services, but also it is potentially very harmful treatment and therefore you want to actually have this done in the safest way possible.

This informant went on to say that, based on the evidence on the risk of treating patients with warfarin, it would be best to locate an anticoagulation service at the hospital, rather than in primary care, where administration of warfarin could be controlled and monitored.

However, there appeared to be few examples where the CG used research evidence to inform a decision that came to the group. In the brachytherapy case, although there was no firm evidence to support its use, the procedure was provided anyway to some patients since charitable funding was available:

S2:...Brachytherapy - this will continue to be on the 'interventions not normally funded' list because there is still no firm evidence to determine its place in treatment BUT since there is money from charitable sources, the PCT will not try to stop it for its residents - merely not put any money into it. This sounds like sophistry and I suppose it is. The whole thing has now been approved by the Board.
(From e-mail correspondence)

More likely, research evidence might be used by the Trust to support funding proposals (hence research evidence could be used as political ammunition):

S3...There is a lot of written evidence to support the use of planning system [for the simulator]...

S3:...We got an external review done of the nursing staff that we have already on the ward...[from] the main cancer hospital in England, and asked their deputy director of nursing to come and review, so [it is] that report that we're basing our nurse establishment requirement.

One informant (S8), a nurse, further suggested that research evidence would be most likely used to *strengthen* a case for a decision already made:

S8:...I definitely use [information] to my best advantage, wherever an issue arises, for example the whole issue around communication skills, then you just quote the Cancer Plan...and, you name it, everything else that contains anything to do with

communication skills. You can use those documents to your advantage and then it's a harder argument for people to discredit.

Consequently, it appears that research evidence does not always influence decision-making to the extent that might be desired by PCT informants (so that evidence is not being used directly to determine decisions made). As discussed in the next section, there appeared to be three reasons why research evidence might not be used directly: research evidence was generally thought of as something divorced from clinical practice; local information was often seen as more valuable, hence research evidence was not necessarily relevant; and there was a perceived lack of appropriate research evidence.

a) Unfamiliarity: research evidence from a "cupboard"

Informants appeared to be "divorced" from using research evidence and felt that gathering and using this information was the responsibility of others:

S15: We would say, "What's the evidence for this?" We'd send [the public health consultant] off into his cupboard and his computer and say, "Go and find some evidence and tell us whether there is any evidence for this or not."

There were some fleeting comments which suggested that no-one knew who should be responsible for using research evidence. This might reflect the complicated nature of the decision-making process, as discussed in the previous chapter. Based on observations of the CG meetings and interviews with the public health consultant, there was minimal use of research evidence in priority setting in practice and was restricted to evidence prepared by the Trust to support funding proposals. This is surprising given that several informants felt the chair of the CG would be relied upon to bring any evidence to meetings.

b) Relevance

Almost all informants suggested that local data about activity within the Trust was often more relevant for priority setting than research evidence:

S9:...We don't have enough information on activity, so we don't actually know what their activity is within the departments, we don't actually know what the demand is coming through and therefore we can't quantify what our backlogs are...

S4:...[I get asked] "How many patients do you think you're gonna be able to put into the trial?" I don't know, you lick your finger and waft it around in the air...

S11:...We are very poor in the NHS about using benchmarking, partly because the NHS is so big, so you've got lots of information but it's about using it constructively...I think the [Trust] will say what's their relative status compared with other areas...but an average is not very helpful...So the case mix will be different, there aren't two hospitals that work exactly in the same way, so benchmarking information is there but is harder to use because people can always find something that's wrong with it.

Part of the problem was the unpredictability of the inflow of patients within the Trust at any one point in time. However, the other problem was that there were inadequate systems in place to record information correctly. This inevitably meant that the CG was more concerned with recording local information correctly during CG meetings and research evidence was of little value in these cases.

c) Availability of evidence

For those with clinical roles in particular, there appeared to be a lack of availability of research evidence relevant to the clinical decisions that needed to be made. Hence, some informants suggested that there was a tendency to rely instead on clinical opinion. For instance, S8 perceived that "robust" evidence required for nursing care was lacking:

S8:...We don't tend to do randomised controlled studies in the sense of what the med profession does. Our research base is much less...there is a lot that needs to be done to get us to that point and just doing a small piece of research doesn't really help, it has to be something that's robust to change practice fundamentally.

It also became apparent during the CG meetings that decisions were generally based around service provision, such as whether to employ oncology nurses in the Trust, for which there was not appropriate research evidence available.

1.2 *"Learnt" evidence: "personal, professional beliefs"*

Although some informants appeared to use research evidence, there were clearly situations where it was not, or could not be, used. In contrast, "learnt" evidence was used to some degree by all informants, and was particularly supported by those with clinical responsibility:

> *SS8: It's subjective, it's based on experience; it's based on my personal, professional beliefs on what's the most important thing at this moment in time.*

> *S1:...The clinician may have decided [the drug] wasn't appropriate, which obviously there isn't much argument against that...*

These informants felt that the clinician's role was to *interpret* the guidance in order to *inform* decisions, suggesting that research evidence could rarely be used directly. For instance, one GP (SS10) claimed that there would always be a choice over the use of cost-effective drugs:

> *SS10:...Basically if you were to take something to lower somebody's blood pressure, you have about 50 different drugs you could potentially use on any one patient. Now how you decide what is the most cost-effective drug to use for that patient is not easy basically...It may be a diabetic which might eliminate some of the drugs, so you may narrow it down to about 4 or 5 potential drugs to use for that patient, some of them might cost £20, some of them might cost hundreds of pounds, some of them might have fewer side effects, it is a balance isn't it? If somebody somewhere has to make the decision, there is no one cost-effective drug because it is always a balance...*

This suggested that learnt evidence, based on personal experience, could have an effect on the use of research evidence. (It further reinforces the point that formal decisions could be reinterpreted at lower levels of decision-making, as raised in the previous chapter).

Apart from clinical level decision makers, other informants, including PCT members, suggested that they often made decisions using their best judgement:

> *S11:...When it comes to a board [of the PCT], all people in the NHS have value judgements but they are not necessarily exposed...Our culture, we cannot escape it...*

One informant from the PCT who was also a member of the CG (S5) suggested that he often made decisions based on his feelings at the time. However, these informants felt that learnt evidence should not cloud rational decision-making. Thus, although they accepted that some other decisions might be informed by learnt evidence, they felt that priority setting should be based on objective criteria. The rest of this chapter considers a specific type of evidence related to economics and economic evaluation.

2. Use of economic terms: scarcity, opportunity cost, and efficiency

This section considers use of economic concepts since these concepts were often raised by informants (although most were prompted by the focus of the topic of the interviews following the workshop in health economics). This suggests that these concepts were not part of typical decision-making and were only discussed in response to attending the workshop and discussion around it.

It is important to note that over one third of all informants had received some kind of training in health economics. This included training during short courses, training as part of degree studies (in economics) in one case and, in another case, a correspondence course from the University of Aberdeen. Three informants with health economics training were members of the CG. The vast majority who had received training were at the PCT/SHA level; no clinicians (hospital doctors/GPs) had undergone training.

2.1 Scarcity: "not a bottomless pit"

During interviews, although there was no mention of the word scarcity, all informants appeared to understand the concept:

> *S15: Within a limited budget, when this would produce, almost double of the expenditure, is this an appropriate use of funds, will it actually identify more people with breast cancer and will it actually save lives at the end of the day? So that's a case where you'd go to [S2] and you'd say, "What's the evidence?" so that we can*

make a decision on affordability and if we spend more on that what are we going to spend a little less on?

S10:...Cost is an issue and you haven't got a bottomless pit, and you have to make priorities don't you?...

They perceived a limited amount of funding available for priorities. SS8, for instance, stated that the priorities the Trust submitted to the CG were not a "wish list" of investments, but were carefully thought out because finance was limited:

S8:...We are not putting forward that enormous great big wish list to make [the Trust] a gold standard perfect cancer unit, so we are already making those decisions, we're saying, "Lets be sensible here, we know that there is a problem with our finances", we are already being rational...

As discussed in the previous chapter, however, whether this was the case, as proposed by S8, would be debated by other informants on the grounds that the Trust were advancing requests to the PCT with a view to obtain as much funding as possible, irrespective of whether programmes were really needed.

2.2 Opportunity cost: "if we spend more on that what are we going to spend a little less on?"

Some informants took note of opportunity cost, whereas others did not appear to be so familiar with the notion. Those who were familiar comprised around half of the informants (although only S3 referred to the term):

SS3:...[Of the CG] cancer's probably pretty rigorous if I think through the health service in general, certainly how the [Trust] has worked in the past, saying "Well we'll have one of these" and not thought through how...you get best value for money, what's the opportunity cost?...

In particular, there was concern among some informants (such as S3 and S6) that the opportunity cost of pursuing NICE drugs was very high:

SS3:...What could one do with that money that could have made us much better off?...

However, it was not at all evident that opportunity cost was really being taken into account during CG meetings. There was never any discussion about what could have been done with the money that was being invested in a particular way and lack of realisation, it seemed, that pursuing one activity might mean forgoing something else.

In practice also, clinicians (SS4, SS8) appeared to argue against opportunity costs. They seemed to find it difficult to think in terms of trading between costs and benefits and felt a duty to provide treatment irrespective of cost:

> *SS8:... My job is to outline what the case of need is, for the service and for patient care, and I can't say because we don't have the money, we don't need what I am suggesting we need, it's not fair on the patients. I also understand that we need to argue the case for cancer, I don't like to think of it affecting patients with heart failure or diabetes, I think that's all hugely emotive when you start rationalising on them, but my job is to say what the need is to deliver effective patient care, so irrespective of whether they tell me there's no money, the argument doesn't change...*

Further, even comments made during interview about opportunity cost were limited to how new money might be spent differently. There was no discussion in interviews about the opportunity costs associated with current provision or attempts to think in terms of disinvestment so as to produce greater overall benefits. These issues were certainly never discussed during CG meetings.

2.3 *Efficiency: "the best value for money"*

A third of the informants used the term "value for money" to denote efficiency. Within the Trust, this involved option appraisal:

> *SS9:...What we do is our own option appraisal here, so if we identify a requirement for a development here, we do our own option appraisal to come up with the best solutions and the best value for money, plus the risks of not doing anything at all...*

However, SS1 was not convinced that value for money was really being taking into account:

SS1:...I'm not sure [the Trust] can tell you how much money they spend on orthopaedics and if they spent it differently whether they could get better value for money out of it...

The comment from SS1 also incorporated the notion of opportunity costs and the idea that undertaking a different practice would be better than current practice.

Although there was mixed opinion as to whether the best value for money was being taken into account, those who seemed to understand the concept of value for money highlighted that it was important to assess whether optimal methods of service delivery were being undertaken, which involved effectiveness as well as cost considerations:

S11: ...You should also state how you would improve efficiency. Now some of that maybe about technology and some of that would be about a judgement about how efficient you are; are you using the best practices in the best possible way?

SS2: ...The terrible thing is if they need further treatment from that, often the [Trust] will repeat some of the tests that are done, so there's both expected gains from a better quality service and there is gross inefficiency.

SS1: ...Locally we are really expected to do certain things and we're having to do the cheapest way of managing to do that probably; it's not always cheapest, it's efficiency as well...

S15:...[Groups such as the CG] might have to look at ways of doing it differently, maybe to do the same thing but do it in a more efficient way...

These comments suggest some understanding of allocative efficiency, or the best way of providing different services. In addition, although no one specifically referred to the term technical efficiency, some PCT informants, as well as Trust and palliative care managers, appeared to understand the concept (related to meeting an objective with the least possible expenditure). The chair and chief executive of the PCT, for instance, wanted to expand some community services and withdraw hospital services, which they felt would save money and provide the same quality of care. One GP (SS1) also perceived that in terms of generic prescribing, the quality of different alternatives was identical:

SS1:...Generic prescribing is all about providing baked beans rather than Heinz baked beans, even though those baked beans may have been made in Bulgaria or something, it's all about finding an equivalent cheaper product and it's a very big thing in general practice...

There was no mention of situations that involved higher costs and higher effectiveness than current practice however (although this may have reflected the poor financial situation of the PCT).

Two informants in managerial positions felt that technical efficiency should be associated with innovative and creative working practices:

S11: So you've got lots of what we call demand models and supply models, which really inform your decision-making about how much you get out of it, but alongside that you've got, "Is the current service efficient or not?" So it's all very well to do a model, which is based on current supply, but is that current supply being sufficiently challenged, so should the length of stay be shorter and then you can get through less throughput and you put everyone on shorter waiting times?

S16:...Radiologists within the Trust say, "We need more CT scanners and we need more radiologists"...So the [Network] said, "We'll test it". So they went out and tested it across the Trusts...and they came out with a report...which demonstrates that the demand and the capacity is actually balanced, there is plenty of capacity...We demonstrated that by new ways of working...working more inventively, would require them not needing a new CT scanner...

The chair of the PCT (S12) was one informant who appeared to want to base priority setting on technical efficiency criteria. For instance, with regard to paediatric oncology services provided locally, he felt that the rational option was to provide these services in one central location:

S12:...There needs to be some rationalisation in the provision of cancer services...For example you said you were providing paediatric cancers at all (X) locations...the cancer network might well say, "Well actually, is that a good idea, is that actually good use of resources or would it be better to centre on one location given they are really not that far away?"...

It is likely that such views would create conflict with some informants' concerns regarding equity. As mentioned in the previous chapter, some felt it would be

infeasible for patients to travel far to access care. Such equity concerns were not voiced by the chair of the PCT however.

On a final point, interestingly, the discussion of efficiency by informants seemed to avoid contemplation of the cut backs which the budget deficit would suggest that the locality faced. All comments raised by informants related to stopping something that was seen to be inefficient; reduction in services was not seen as an option.

2.4 Economic evaluation: "cost effectiveness" & "cost benefit analysis"

Around a quarter of informants from a range of backgrounds referred to the terms "cost-effectiveness" and "cost-benefit analysis." In most cases, it was not evident that these terms were really understood, and they seemed to be used in a different way than would be understood by health economists. For instance, in relation to outcome measures typically used in economic evaluation, although SS17 mentioned the term "QALY", she felt (despite having received health economics training) that she did not understand what the term encompassed and used it to reflect outcomes in general.

In other cases, it appeared that understanding of the term economic evaluation was restricted to what was generated by NICE guidance. For instance, SS4 referred to a threshold cost per QALY of £30,000 used by NICE, although, interestingly, he believed that his own experience would be the most important factor in clinical decision-making:

> *OA: What's your viewpoint as a clinician? The cost of these drugs in comparison to the length of life saved...*
> *SS4: Well I could cheat couldn't I and say, "Well NICE use £30,000 for one QALY, so a course of rituximab is less than £30,000." So a year is something I would be hoping to get out of a course of ritiximab. If I didn't feel that a patient was likely to get that sort of response then I wouldn't be suggesting it. But it's quite a difficult decision to make. It comes down to experience; you don't always get it right.*

It appeared that although informants were familiar with measuring benefits, they were unfamiliar with health economists' methods for measuring outcomes. In addition, they seemed unfamiliar with valuing and measuring costs, as would be typically undertaken in an economic evaluation.

In summary, decision makers, to a greater or lesser degree depending on their professional role, understood the following economic concepts: scarcity, opportunity cost, and some notion of efficiency. (Note that generally those who were absent from the workshop but were familiar with health economics' concepts showed a greater understanding of these concepts than those who attended the workshop. Given the nature and length of previous training, compared with the two-hour workshop, this is not surprising). However, although most informants were familiar with the terms used by health economists, some (SS1, SS9, SS6) appeared to be confused about how economic principles could be incorporated into priority setting in practice due to lack of financial resources. SS6 stated that in other financial climates, where there was more money available, economics might be used as an aid to decision-making. Others had similar perceptions:

> *OA:...Could what you have learnt at the workshop be useful?*
> *SS9: Yes definitely, but also it always comes down to the cheapest option...*

> *SS1:...It's all about saving costs as far as we are concerned...We can spend an awful lot of money, more money on health care than we do, and therefore we're forever looking at ways of being more cost-effective, or more economic, or indeed reducing choices for patients so that it saves money...*

> *SS1:...We are all about cost containment essentially and trying to develop services essentially within a cost envelope, which for us is an overspent envelope, so the economics are such that we are in an overspent situation and we're trying to do developments within that...I think it is just economics per se which describes the environment you're trying to operate, the financial environment in which you're trying to operate...*

3. Use of economic evaluation as an aid to priority setting

This section explores the use of evidence from economic evaluation as an aid to priority setting. Although there was found to be no use of published economic

evaluation, there was use, in theory, of economics as a way of prioritising at different levels of local decision-making.

3.1 PCT: "rationality" or "opinion and consensus & policy"?

According to some PCT informants, the board and executive committee of the PCT first examined the clinical effectiveness of a programme and then the costs or outcomes associated with pursuing it. Some PCT informants saw the PCT as acting "rationally" in this respect. Although this term would not fit well with the economists' standard definition of rationality (evoking certain objectives being pursued, together with the maximisation of utility), it is likely that the notion expressed here incorporates the idea that costs and benefits of alternative courses of action are evaluated, in order to make an informed decision:

> *S11:...Knowing the costs, knowing you've got the right information, building a case about arguing it rationally. So you are usually talking about things like how much it will cost, how much will you produce, who will benefit, who will lose?...*

Although there was no apparent use of published economic evaluation to inform decision-making, and no cases where in-house evaluations had been conducted and used, PCT informants suggested that there were instances where option appraisal provided similar evidence. Upon reviewing these appraisals, however, there was no systematic identification or valuation of costs and benefits. In particular, a comprehensive assessment of the benefits was missing. Hence some informants stated explicitly that health economics was not being used:

> *S11:...We do use option appraisal but they tend not to be at the level of health economics. Whether it's value for money and affordability would be two big drivers in our decision-making.*
>
> *S11: I remember the days when all Health Authorities were going to start using health economics to make their decisions. But we here have not been in a position actually...*
>
> *S2:...[Of health economics not being used] It is a great source of sadness. The only process where I know it is going on is in the NICE process. Everything else is, frankly, opinion and consensus and policy.*

3.2 CG: *"the quicksand of reality"*

Some informants, notably from the PCT, felt that the CG was adopting a rational approach to prioritising, again in the sense of using costs and benefits to make the 'best' decision. Indeed, the chair of the CG in particular was very keen to adopt a more rational basis for decision-making within the CG and had been encouraged by the workshop in health economics:

> *S2: I like to think that personally I have got more of a kind of desire to drive things on a cost and benefit approach already, but that my enthusiasm for that is strengthened by events like [the workshop] and I think to myself once again that this is the right way to do it...*

Several other informants, such as S1 and S3, also perceived the advantage of using a weighting mechanism to rank CG priorities (notably this was discussed before the workshop). S1 referred to this as a "common sense approach", which he believed was being used for prioritising community services:

> *S1:...In our local community, over community services, we've tried to score things basically, we've tried to get a way of prioritisation, each with weighted factors and then we've tried to score each thing on a weighting, and basically the ones with the highest numbers at the end of the day are the ones that get done. That's <u>not</u> how we've done it for the [CG]...*

In the CG, scoring of priorities was perceived as being hard to conduct since it was "very difficult to comparatively score and to get it right" (S1). He felt that community services were easier to prioritise because:

> *S1:...This is something we can do, we both pay for and provide the service, and commission the service, we do the whole lot, and then if we want to change it we can, we can stop doing it - we have to consult with the public and this sort of thing, but it can be done...*

Apart from difficulties in comparing different priorities, there appeared to be two additional problems in scoring priorities for cancer care. Firstly, in cancer care there were few decisions to make locally, since there were strong national dictates,

with regard to the type of treatments and interventions that cancer patients should be able to receive (although such restrictions did not only apply to cancer care):

> *S11:...We've never had to make a big decision about whether to spend money on cancer or coronary heart disease, because we are so clear about what the targets are and because there is no longer clarity about whether the services are important...so it's no longer easy to say, "Well therefore that gives us the rationale for doing X, Y and Z."*

> *S11:...Once upon a time, much more local decision-making – can we afford it and does it make sense? Now we've got a national body that tells us, anything that NICE tells us effectively we have to implement so they make announcements about whether a certain drug should be available on the NHS, whether or not we should be providing IVF treatment, so again...making those decisions for us...*

However, the existence of national dictates was not the only reason for lack of use of economic evaluation and there appeared to be another, more complex, problem hindering priority setting, although this was not always recognised explicitly by informants in interview. The issue centred on CG members not always acting as if resources were scarce, even when they were supposed to be adopting a population perspective. Often programmes were advanced in the form of a "wish list". There were an ever-increasing number of investment opportunities being brought to the CG, despite the acknowledgement that financial resources were extremely limited, with limited thought for disinvestments that could be made.

It is not surprising that given this context, there was no use of economic evaluation at the CG. On a few occasions, the chair of the CG referred to published economic evaluations of cervical and breast cancer screening, but this was in passing and his comments did not form the basis of any specific argument, so that the evidence was not subsequently discussed. In fact, there was only one specific example where a published economic evaluation was brought to the CG. Here, evidence of the costs and benefits of a high cost procedure (brachytherapy) was brought to the CG by an invited speaker. Some informants felt that the evidence could not be applied to local settings and questioned whether there was sufficient physical capacity to provide treatment. Clinicians also voiced concerns that the costs of the therapy should be borne by the pharmaceutical company endorsing the trial. They might

have been concerned to ensure that financial resources were not drawn from their funds.

There appeared to be no effect on the decision-making process or decisions made subsequent to the workshop. The format of the meetings was the same, there was no disinvestment list, and there was no attempt to try and revise/reconsider some of the decisions that had been made previously. This is perhaps unsurprising given the timing of the workshop (in that most of the decisions/priorities had already been set for the next financial year or so) and the duration of the workshop (only one workshop was help, where in practice it might have been better to have two or three).

3.3 Trust: "option appraisal"

As discussed previously, option appraisal lists the costs of the proposal, although benefits were not defined in the way health economists would typically think of. Instead, benefit statements tended to concern cost savings, meeting targets, and/or preventing clinical risk to patients. Costing was also not achieved in a rigorous way, as would be typical in a research based economic evaluation. Option appraisal was a more local assessment in some cases:

> *SS9: We consider all of the options, so, say for example, we wanted to develop brachytherapy...I will assess what's the risk of us not doing anything at all, what is the risk of us implementing it, what is the risk of implementing it as a clinical trial, and also considering the other options of sending it to another hospital or sending it privately. So doing an options appraisal means that you have covered everything, so when you're presenting a case, what you're saying is "Yes, we want to develop it here on the site, and these are the reasons why we wouldn't consider it elsewhere".*

Option appraisal was not typical economic evaluations, but they did seem to provide a way of assessing the cost and benefits of programmes and their alternatives, which incorporated economic concepts alongside other objectives (for instance guidance from NICE and the DoH). Palliative care also used some form of needs assessment, although it was recognised by SS17 that evidence was scarce for the type of decisions they needed to make. There was only one mention of economic evaluation, with regard to a study which had been performed about

fifteen years previously, although no details of the study were available and SS17 did not know the study's effect on decision-making.

3.4 Clinicians: "balancing cost against quality of life"

Cost-effective drug prescribing (by GPs) appeared to be the main way in which economic evaluation might be used in decision-making by clinicians:

> *S1:...Every single patient I see I make a decision and I don't necessarily give them the best treatment that there might be, because it happens to be the most expensive...*

> *S1:...There are some very good ulcer drugs and there are some less good cheaper ones, so we tend to give them the less good cheaper ones because it saves money...*

There was also some indication of age-based rationing, which incorporated notions of costs and benefits:

> *SS10:...To some extent you're balancing cost against quality of life...If somebody was younger you may give them a more expensive drug with a better side effect profile. If they were older, they may be more tolerant, they may be on other medication, so you are less concerned with side effects...*

However, it remained the responsibility of the GP to decide what was cost-effective, as there was often a choice between many cost-effective treatments and the GP would have to make a decision for an individual patient.

4. Explanations for limited use of economic evaluation

Apart from there being no use of published economic evaluation at the local level, there was also a lack of interest among some to incorporate an economic way of thinking into priority setting. There appeared to be three main reasons why economic evaluation was not used to inform priority setting: evidence from economic evaluation was not relevant to decisions made; there was a lack of local basis for decision-making, meaning that decisions were made about how to achieve national directives; and there were other incentives among clinicians, relating to difficulties with rationing and wanting to avoid blame from rationing care.

4.1 Evidence not relevant: "doesn't often centre around some of the issues that I am concerned about"

Published economic evaluations were not relevant to local priority setting, since important issues, discussed during meetings were whether to employ additional staff or where to locate care. Decisions concerned, for instance:

> *S1:...a particular nurse that should be employed but isn't, or particular shortage of one particular modality...*

Such decisions were not easily identifiable with the usual topics addressed in economic evaluation.

Two informants (SS8, SS17) spontaneously offered specific examples of where published economic evaluations might be insufficient for decision-making locally, where they were unable to capture effects on quality of life:

> *SS8:...[Economic evaluation] doesn't often centre around some of the issues that I am concerned about in nursing care...*

> *SS17:...It is not easy to define what the benefits will be...How do you define psychological support if you invest in nurses to provide critical support for people with cancer? How do you define that with an outcome and relate that to cost-effectiveness?...It would be difficult to say, "It would prevent that number of people from getting depressed."*

> *SS17:...How do you quantify the benefits of a user group, carer and patient views, and yet that is a really important priority...*

This suggests that the type of outcome measure typically associated with published economic evaluation is not comparable to the benefit measures viewed as important by decision makers [mainly concerning emotional and psychological benefits, such as preferences for dying at home (SS17) or provision of videotapes for cancer patients on the development of their condition (S8)]. Furthermore, there was concern that economic evaluations produced by NICE were not in accordance with the values important for patients and therefore decision makers:

> *S3:...NICE guidance that says, "You can give this type of drug to this particular class of patient...and it will extend their life for 3 months",...but actually, people have got to think through what that 3 months of life might be like...*

The point, that published economic evaluations would not be relevant to local decision-making, was further reiterated by a 'project' that the researcher undertook as an aside for the chair of the CG. A major area that the CG were involved in debating concerned an extreme backlog of patients in the Trust waiting for endoscopies. Some of these patients had suspected cancer and had exceeded maximum wait time targets. In order to resolve this problem, the chair of the CG was keen to relieve the pressure on the Trust and allow a proportion of endoscopies to be performed in primary care, by an experienced nurse or specialist GP. However, no economic evaluation could be found to inform this decision-making, nor was it possible, within the time frame, to estimate the costs or benefits associated with ways of dealing with this backlog of patients. Eventually, a strategy was developed by the chair of the CG to manage the demand for endoscopy services, by developing an appropriately skilled workforce (involving training nurses and GPs in performing endoscopies). This decision was based on a personal opinion of the chair of the CG rather than informed by evidence (although the Government was encouraging specialist GPs).

4.2 No decisions made: "we don't often have that freedom of decision"

As discussed in chapter 4, there appeared to be little freedom for decision-making at the local level. There were two reasons for this, related to the political imperatives and lack of financial resources, both of which S2 described as "the quicksand of reality" (pursuing national policy in turn meant limited funds available for local policy). There was a perception among some informants that Government policy ignored economic rationale:

> *SS6:...If [politicians and civil servants] understood health economics better we wouldn't be driving some of these targets.*

Around two thirds of informants felt that targets dictated priorities and restricted the incorporation of an economic way of thinking in decision-making. For instance:

> *S6:...You think you're going along and something comes that completely scuppers the plans that you had, usually new Government targets that mean you've got no money left for anything at all...So the new targets for cervical cancer screening for instance, economically they are completely a waste of money, but they are going to drain all the plans that we would have had for two years time, but that's life in the NHS... They haven't been properly thought through so the economic implications, at a local level, are simply horrendous compared to everything else that's happening.*

> *S11: ...I would say to [the public health director], "What's the evidence for doing this and what's the cost of making that decision compared to the benefit?" But as we have no money, we don't often have that freedom of decision. Any money we've got will be spent on national policy, so we are very much, at primary care trust level, even I think at the strategic level as well, driven by national policy.*

These feelings were strongly reflected during the workshop discussion, where national directives dominated local priorities. Of the workshop, two informants said that:

> *SS4:...It seems to me that the prioritisation came in line with entirely what the Government were putting forward and forced us to ignore all the other important issues...*

> *S9:...In an area such as cancer where the Government set so many "must do" targets this will be very difficult to achieve practically.*
> *(From evaluation of workshop form)*

On the other hand, one informant (S5) had a very different view of the extent to which Government policy restricted the use of an economics way of thinking. He felt that most decision makers did not view the targets, as they should correctly be seen, as an end product that could be reached in different ways. For instance, S5 was of the opinion that there were two possible ways of attaining the target related to the maximum wait in A&E not exceeding four hours. One was to employ additional staff and the other was to invest time and money into changing habits and behaviours so that people worked more effectively. S5 felt that in most cases the first option, employing additional staff, was chosen, because of the "myopic" nature of local decision-making (employing additional staff was the easiest option

in the short run). However, the rebuttal to this would be, as SS1 suggested, that for most decisions there was no choice: "cervical cytology screening...has to be done, there are no other ways of doing it..."

According to two informants (S3, S7) lack of financial resources in the locality was a potential barrier to using economic evaluation. They felt that because of the focus on cost containment, there were few local decisions to make:

> *S3:...If you were having this conversation with the PCTs, I am absolutely sure that they would say, "Blow to the economic evaluation, the only thing that matters is do we have the money to pay for it."*

A particular aspect of this problem perceived by one informant (S7) was the need to fit in with the short-term orientation of the NHS, even if the economic evaluation study showed the intervention to be "cost-neutral" over time.

4.3 Incentives: "doctors tend to make decisions on the individual"

Among some clinically based informants, there appeared to be few incentives to adopt a wider perspective (as typically assumed in economic evaluation) as they associated their role with responsibility for the individual patient, rather than a community or population of patients:

> *SS6:...If you're looking at... health economics, I think oncologists would be swamped because doctors tend to make decisions on the individual, not in the general sense...*

Even when clinical informants were taking a population role, they tended to bring with them the viewpoint associated with their individual role. Consequently, they appeared reluctant to make rationing decisions or to deny care to patients, because it conflicted with their usual role. There were two aspects to this: the difficulties, they felt, with rationing; and the responsibility attached to rationing care.

a) Difficulties with rationing: "it's very difficult to deny a single patient"

These informants suggested that rationing care was difficult because it was hard to be objective and unemotional:

> *SS8:...Giving up is often quite difficult, so it's often easier to them [the clinicians] to say, "Lets keep going, lets keep working on this cancer", than to have the difficult conversation about, "Where do we go from here, what's in your best interest?"*
>
> *SS4:...It's all very well to take yourself away from the one-to-one consultation...the patient wants you to do something, you have it in your power to do...*
>
> *SS1:...It's very difficult to deny a single patient that drug because it's expensive...*
>
> *SS1:...The conflict between the greatest good for the greatest number or the greatest good for an individual patient...*

Such informants had individual patient responsibilities from which they often appeared to be unable to divorce themselves when making population level decisions within the CG. Hospital clinicians, in particular, found rationing difficult because they did not feel it was appropriate to base decisions on monetary costs:

> *SS8: My job is to outline what the case of need is for the service and for patient care...irrespective of whether they tell me there's no money...*

In contrast, it could be argued that GPs were able to make some trade-offs of cost against quality of life, as shown previously. The issue of GP rationing is probably less stark because they are not usually responsible for deciding between the life and death of a patient.

It was unclear from the research how clinicians' focus purely upon individuals might be overcome since they are always likely to have a patient centred perspective. However, as discussed in the conclusion to this chapter, enabling clinicians to understand the principles of economics and recognising that, for instance, treating one patient could mean not treating other patients (*i.e.* opportunity cost), could be helpful in this respect.

b) Avoidance of blame: "it's not my job particularly to decide"

Some clinical informants (SS1, SS4, SS8) felt they did not want to be responsible for rationing treatments between individuals. Another clinician, who attended the CG but who was not available for interview, appeared to also take this stance. SS1 felt that it was the responsibility of politicians to specify what was affordable rather than clinicians, and pointed to the problems with equity if rationing was undertaken by the latter:

> *SS1:...Politicians need to...be a bit more upfront about what our current economy can afford and what it can't afford and give us some precise guidance...rather than leaving it to us to make some local decisions which will then result in postcode treatment...*

Other informants, notably a hospital clinician and nurse, asserted that PCT commissioners should be responsible for difficult decisions that essentially involved someone's life. They wanted to be sure that if they rationed care, the responsibility for dealing with any public or individual resistance would not rest with them:

> *SS4:...I brought out my question of drugs developments and how clinicians were supposed to deal with them and this is where I had my answer from the PCT chief executive, basically saying, "It's up to the clinician. There isn't any extra money in the pot, we are very sorry". That is not supporting clinicians- that is not saying, "I understand the difficulties that you are having, maybe we ought to concentrate on this or that."...We need somebody that is going to back us up and say, "Yes [he] was quite right when he denied the patient this drug, we aren't able to give it and the reason is we are overspent." Somebody who can stand up on the telly when the patient goes to their member of Parliament...*

> *SS8: As clinicians, when we are face-to-face with patients, if someone comes to us and says, "According to this document I meant to have my scan within a certain period of time", why should we be the ones to explain to the patients that actually the PCTs didn't fund this?...The onus shouldn't be on the clinicians to inform the patients on a one-to-one basis in a such emotively fraught situation.*

In the PCTs defence, some felt that explicit rationing was hindered by problems with the media creating adverse publicity, especially relying on powerful lobby groups. S7 felt that an action might be "cost-effective", "clinically safe", and

"rational", but if there were "too much noise politically", the PCT would be unable to enforce the action. In addition, SS6 felt that clinicians were aware of the threat of being "pilloried" in the press if they had not offered treatment to patients for monetary reasons. However, fear of being seen to be cost-driven was an inadequate explanation for the CG not using evidence to inform local decisions. The researcher's efforts to find evidence that concerned some of the local decisions being made was not fruitful and hence it appeared that relevant evidence was lacking.

5. Potential to facilitate use of evaluation: "[we] are not health economists; we need assistance when it comes to these difficult decisions"

Findings revealed that the main way in which economic evaluation might be used was if decision makers were to receive training or expert help in explicit priority setting in decision-making. Several informants recognised the difficulties in trying to decide between priorities and that they needed assistance in prioritising. Part of the problem rested in the comparison of diverse priorities:

> *S1:...Basically you are having to prioritise a lot of, sometimes, quite small requests and you can get something like the request for a CT scanner or something that's going to cost half a million or something compared against the requirement for another couple of secretaries in the oncology department because the system is not working 'cos it's short of two members of staff... And trying to make a decision, trying to balance those two and actually trying to say, "We can support one but not the other" and which one is it that actually we are going to support is very difficult because they're completely different things...*

SS17 also felt that it was difficult to compare priorities that concerned quality of life, such as in assessing the value for patients of being allowed to die at home, rather than in care. For SS17, it was difficult to comprehend how an economic evaluation could address this issue:

> *SS17:...It may be very easy to compare some of these things and certainly in relation to breast cancer screening and cervical cancer screening we should have some*

evidence to support that decision-making...but how do you compare them with the ones that are not so easy and it is about quality of life rather than more absolute health outcomes?...

However, there was also a clear lack of knowledge of economic evaluation among decision makers:

SS17:...I don't know whether everyone understands QALYs, that was taken as a given really, but, I don't know much about quality of life indicators, I wouldn't be able to apply it, unless there was somebody there at future meetings to explain it...

Even informants with some background or experience in economics mistakenly associated health economics with money:

SS1: I think we apply economics, I don't think economics is something you understand, it's just part of a decision-making process, you have to have an economic view as to something that involves money and that sort of thing, when making a decision...

This suggests a sustained commitment to educating decision makers' in health economics throughout the process of decision-making would be worthwhile. Furthermore, it might even be worth highlighting the importance to decision makers of the role of health economists, given that one informant (SS6) felt that an epidemiologist was needed to assess the cost-effectiveness of services provided locally:

SS6:...In terms of what is the most cost-effective for the whole population...that's actually very difficult to sort out and expertise isn't there, you'd have to be an epidemiologist to even sort of grapple with that...

Several informants felt that it would be beneficial to rank priorities in order of importance, although there appeared to be limited scope for achieving this in the CG in practice. With respect to a decision about where to locate a breast clinic, SS2 felt that it would be necessary to undertake the following, which had not been done previously because it was a "big piece of work":

SS2:...You'd look at the costs, that wouldn't be difficult to do. The benefits would not be utility type benefits and it wouldn't be particularly rigorous. I think the way we'd look at benefits would be almost a kind of impact assessment, we'd make a list essentially of all the ways you'd assess benefits, and it would be things like access, which is partly about travel and partly about...discomfort and distress and also about volumes to deal with capacity...If we were really rigorous we would score those criteria on one to five, where one is not terribly impressive and five is a good thing...

This comment suggests that maximising health was not the only criterion for decision makers, and that other factors were relevant, such as access, discomfort and distress for patients. SS2 felt that measuring costs would not be difficult, but benefits would be harder to value, supporting the comments made by SS17.

SS2 suggested using an "impact assessment", examining the costs and benefits of programmes, which would be a rigorous approach and for which practical help would be beneficial. This opened the potential for an economic approach to priority setting:

SS2:...Where we argue and we mostly work is that fluctuating amount which is making changes - either buying extra things or changing things. It's often said that if we were to discuss changes in the total budget, not just the margin, the tiny bit that we add or subtract, we would have more control...

Although this comment arose after the workshop, other suggestions along the same lines were made before (for example, in terms of scoring priorities). From observation of the CG, it is likely that co-operation with other decision makers would be necessary in order to implement this approach. Apart from issues such as trust and partnership working highlighted in the previous chapter, there might be value in initiatives aimed at increasing knowledge of economics among decision makers, perhaps through workshop(s), similar to the one carried out in this study:

SS2:...The concepts that came out, that were elaborated, were not new to me. But they were very clearly new to others round the table. At first I thought they were going to dismiss a lot of it and say, "This is common sense, we know all of this", but I think several of them hadn't realised that there was a systematic and almost learned approach...

SS9:...There were a lot of things that I never appreciated before, about how decisions could be made, about setting priorities, so the whole economics part of it...

SS8:...Perhaps it did raise my awareness a bit more about the frameworks within which you can prioritise...

6. Conclusion

There was no evidence in this study of published economic evaluations being used to inform decision-making. Some form of priority setting did exist at the local level however. Option appraisal, encompassing an understanding of economic concepts such as scarcity and opportunity costs, was conducted. In addition, GPs claimed to prescribe cost-effectively (although it was not possible within the scope of this study to observe clinical decision-making by GPs to confirm this).

There were three explanations for the limited role of economic evaluation locally: lack of relevance of studies to decisions being made; lack of ability to ration locally on areas important for the local level; and lack of incentives to ration care. The barriers mentioned in this chapter are not entirely in line with those in chapter 2. In the literature, lack of relevance of studies was not considered as very important, and there was greater emphasis on the bias and quality of economic evaluation. The notion that decision-making might not be achievable locally, largely because of national policies, has not been explored in-depth in chapter 2. Incentives to ration care are also vaguely considered in decision-making.

There is little indication that the accessibility of economic evaluation (in terms of quality of studies and time to access studies) was a barrier to use for decision makers in this study, although availability of appropriate topics for the types of decisions being made was lacking. This does not mean that accessibility would not be a major barrier to the use of published economic evaluation. On the contrary, in this particular case, decision makers did not ever reach the issue of accessing published economic evaluation because of the other constraining factors, such as decisions being focused on the attainment of political objectives. Although one informant (SS6) stated the use of "surrogate data and assumptions" in published

economic evaluations had caused him concern, he said that this applied to any research evidence and was not based on his own experience. Again, it is likely that because decision makers never reached the issue of accessing economic evaluation, they were not concerned with the quality of studies.

Findings of this research have implications for the work of health economists. For instance, it is difficult to understand how QALYs and QALY league tables, discussed in chapter 2, would have practicality at the local level. Furthermore, there is little to suggest that there would be any value in further refining methodology of economic evaluation if the objective is to encourage use of economic evaluation among decision makers locally. Although none of the respondents in the study proposed a way forward for economics (since, as mentioned in chapter 3 they were not aware of the focus of research) health economists have an important role in being able to articulate economic principles among decision makers, since this study found that only a proportion of decision makers understood economic terms and even then they did not appear to know how economics could be useful for priority setting. Specifically, it would be useful to create awareness among decision makers of the possibilities for disinvestment. In addition, decision makers should be given more scope to feel empowered to make local decisions, creating incentives to ration care.

The following chapter explores how health economists view the use of economic evaluation in local decision-making. The data from the study of health economists are presented separately from the study of local decision makers and limited comparisons are made between the two groups. Data from both studies are more fully compared and contrasted in the discussion chapter of this thesis (chapter 7).

Chapter 6: Health economists' views

This chapter investigates health economists' views about health care decision-making and the use of economic evaluation at local and national levels. The first section of this chapter presents informants' views about health care decision-making in the NHS. This is followed by an exploration of views about the use of economic evaluation at national and local levels, with the fourth section exploring the perceived barriers. Measures that health economists perceive to be important in increasing the use of economic evaluation in the NHS are also presented. The final section provides a brief conclusion to the chapter.

As detailed in Table 6.1, informants were working, or had previously worked, at the local level[xviii]; had an academic profession; and/or were members of national decision-making bodies, such as NICE, or priority setting forums.[ixx] Most informants had more than one role; only two informants were solely academic health economists. The largest group of health economists consisted of those who were largely academic but were also members of national decision-making bodies or priority setting forums. Only three health economists were solely in local decision-making positions, working in groups such as PCTs as health economists. All informants were senior health economists.

Table 6.1: summary of role of health economists

Role	No. Interviewed
Academic	12
National decision-making body/priority setting forum	10
Local decision-making	6
TOTAL	15

[xviii] Equivalent in size to a group of PCTs, similar to the fieldwork study.

[ixx] For confidentiality reasons, the names of these forums and their geographical locations have not been specified. However, in general, according to informants, the priority setting forums include representation from decision makers, both from the commissioning and providing side of health care, and, in some instances, patients and health economists. The purpose of forums was to discuss issues around decision-making for difficult cases, in particular where clinicians had requested funding for a treatment not routinely prescribed in the NHS.

1. The decision-making process: "a hard question"

This section addresses the main themes surrounding the decision-making process that arose from the interviews with health economists. These concern the model of decision-making typically assumed, notions of power, the types of decisions made, and national constraints.

1.1 Stylised model of decision-making

Most academic health economists with no previous local experience had limited knowledge about how decision-making operated at the local level. Although two informants (E2, E4) referred to the "levels" of decision-making, they seemed not to fully comprehend how these levels operated and affected the decisions made. Academic health economists felt that an amorphous group labelled "decision makers" within "the PCT" (or even "decision maker" as the PCT) was responsible for priority setting locally. Often they were unable to specify the roles and responsibilities of these decision makers, as for instance:

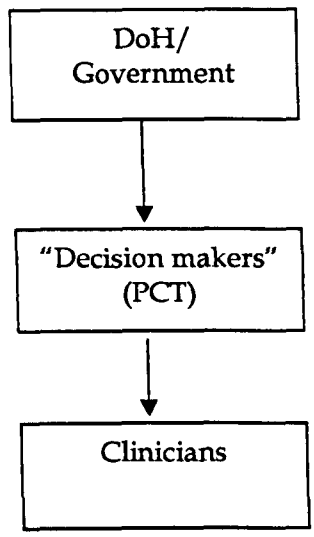
> *OA...Who do you think are responsible for decision-making in the NHS?*
> *E8:...[.3] Oh gosh that's a hard question.*

Most academic health economists perceived a stylised model of decision-making:

> *E7:...Policy makers [are those] at the ultimate level or whoever is responsible for providing services, so in England and Wales, [it is] the Department of Health [and] the National Institute of Clinical Excellence...*
>
> *E12:...NHS decision makers includes NICE at the national level through to mainly PCTs and possibly hospitals...*

The representation of decision-making assumed by some health economists interviewed is represented in Figure 6.1:

Figure 6.1: stylised decision-making



They placed the DoH/Government at the top of a hierarchy, clinicians at the bottom, and the "decision maker" covering all (population) levels of decision-making in between.

> *E2:...I suppose you could argue that in the end, in a sense, the Secretary of State is the decision maker for pretty well everything in the health service...*

> *E4:...Local decision makers, who are making perhaps decisions for the local area, like the old Health Authorities and the new PCTs; people concerned with the practical management of health care resources in their localities...*

1.2 Clinicians

Although most academic health economists perceived a stylised model of decision-making, the majority, irrespective of background, suggested there was power residing with clinicians (hospital doctors and GPs) for local decision-making. However, because of this power, they felt it was often difficult to understand how decisions were made:

> *E3:...The processes by which decisions are made on non-drug technologies in hospitals is very unclear, and is, almost certainly, made by clinicians using their best judgement...*

E7:...My perception is that there's no standard pattern as to who determines decision-making...it's maybe clinicians...I think ultimately a lot of power is resting with clinicians...

E13:...GPs are an enormous decision-making [body], as are individual consultants...they do have a huge amount of power...

Some informants suggested that decisions made by clinicians could distort, or override, decisions previously made by higher authorities. E3 offered the example of individual clinicians treating coronary artery disease deciding to use a particular procedure, which had not been agreed by the DoH. This informant said that the procedure was so widely used that by the time NICE conducted their evaluation they could not object to the established practice.

Three informants (E7, E8, E12) without local experience felt that clinician discretion over treatments was inefficient and that treatment decisions should be made at a "higher" level of decision-making:

E12:...I am not convinced GPs should be making...decisions [about which treatments to provide]...the broader brush questions about who you should make statins available to...those sorts of decisions I think really ought to be made at a higher level....

E8:...The hospital isn't the biscuit factory and in the biscuit factory the people who make the decisions are the managers and the workforce actually carry them out, but in the hospital, the consultants are of the workforce, but they don't listen, it's as if you have a biscuit factory where the workers were determining what type of biscuits they were going to produce and what type of production techniques they were going to use, and what raw materials they were going to use, and no biscuit factory could stay in business that way, but that's what happens in a hospital, because it's the people on the ground who...make the decision about what biscuits to produce and what production processes to use, and we live in a world where it is very, very difficult to take that away from them...

E8's comment, although showing awareness of clinical decision-making, appears to ignore the complexity of health care decision-making. E8 felt that ideally the purchaser, or the PCT, should be responsible for deciding which services or treatments (not) to provide. He felt it would be more appropriate to impose service agreements on clinicians to ensure they were providing what was agreed and

nothing else. He also felt that due to the autonomy of individual clinicians in the system, this process was not working in practice. This is interesting because it suggests that the model provided in Figure 6.1 is not really the way some, such as E8, believed decisions are made, but the way that they would *like* them to be made, following classic rationality.

In contrast, the majority of informants with local experience did not allude to a stylised model of decision-making. Both E6 and E10, for instance, referred to two levels of local decision-making not corresponding to Figure 6.1. Here, one level of decision-making involved programme groups making decisions about particular disease or treatment areas.[xx] The other level consisted of members of the PCT responsible for allocating financial resources between different programmes, such as cancer and CHD.

1.3 Types of decisions made

Having greater familiarity with the decision-making process, those with local experience were able to offer examples of decisions made at the local level. Decisions at the local level tended to concern the "reconfiguration" of services within secondary care:

> *E13:...The biggest decisions that we make are not around technologies, they're around individuals and labour is the really scary decisions that we make. So it is not, "Should a consultant provide drug X?" it's, "Should we have that consultant?"...*

This point, that the majority of local decisions involved whether to employ additional staff, or where and how to locate care, was not referred to by any of the academic health economists. The latter group tended to regard local decision-making as concerning the provision of drugs or procedures, but E13's experience is certainly backed up by the fieldwork reported in chapters 4 and 5 here.

[xx] Based upon the description, these programme groups seem to be similar to the CG.

1.4 National constraints

Similar to decision makers interviewed for this fieldwork, most informants felt that decision-making at the local level was being constrained by national policy:

> *E6: I see the local level as being more and more constrained...the targets ... seems to me to be what's driving the system.*

> *E3: Ohh no, hardly any decision-making is left at local level...[because of decisions made by NICE and the DoH].*

Those with local experience felt that local decision-making was also constrained by other factors, such as the constant change in the organisation of the NHS, the need to simultaneously balance the budget and meet the targets, and the lack of financial resources to implement change. Informants did not comment on what they felt to be an appropriate basis for local level decision-making, instead focusing on what they believed to be the constraints in the pursuit of efficiency.

2. Use of economic evaluation at the national level

The main focus of the interviews with health economists was their views and opinions about the use of economic evaluation at the national level (involving the DoH and NICE) and particularly the local level.

2.1 The DoH and NICE

Informants perceived several outlets for economic evaluation at the national level. These included NICE, Health Technology Assessment (HTA) reports, NSFs, guidelines for the use of cost-effective prescribing, and screening recommendations. The consensus was that the DoH and NICE were the main target audiences for economic evaluation:

> *E3:...The DoH is presumably the target audience in mind...*

> *E15:...The target audience...is clearly likely to be a relatively small number of individuals...the DoH...*

E2:...I would argue that increasingly health economic studies are being written and presented for fairly defined decision makers...NICE is a prime example of that.

Several informants believed that NICE provides an important "audience" (E3) or "customer" (E5) for economic evaluation, as well as a "success story" (E8) for health economists. However, they also suggested that the exact extent of use of economic evaluation by NICE was unclear and they pointed to the ambiguous criteria used by NICE in their decision-making. For E1, the question of how NICE reached their decisions was a "deep psychological question". Although these informants perceived that other criteria, such as burden of disease, were being used in NICE decision-making, they were unaware of the extent of the influence of these factors. One informant (E14) believed that economic evaluation was used as an ornament or "bauble" on the guidance (suggesting that there were other factors in NICE's decision-making that were more important). Furthermore, another informant (E5) felt that, where economic evaluation was used by NICE, the evidence was often part of a large trial, rendering it difficult to assess the impact of the economics on the decision.

This ambiguity about the exact use of economic evaluation by NICE extended to the debate on the existence of a threshold cost per QALY. Some informants claimed that often programmes recommended by NICE exceeded the threshold and other programmes were rejected, even though their cost per QALY was lower than the threshold:

E9:...NICE operates to a sort of cost per QALY threshold of £30,000; we can debate it, I suppose, and they would deny it, but when you look at their appraisals, there are some which have gone through at above £30,000 and some which haven't gone through at below £30,000, so I don't think that's a threshold which is established in stone.

One informant felt that NICE would be reluctant to admit to a threshold cost per QALY for fear of that threshold being contended:

E3...If NICE was explicit and said, "Look there's a threshold of X cost per QALY" and it said, "Yes" to something that's X plus Y, then by implication the other factors are worth Y per QALY. And that's tricky because that would then constrain NICE's

future decision-making because it would then mean, "Look you said yes to two things. One is X plus Y and the other is X plus Z"...

Another possible reason for not establishing a formal threshold cost per QALY was related to the questionable nature of the ultimate power of NICE's decision-making. Some informants alluded to a power struggle between the DoH and NICE. These informants felt that the DoH was able to overturn NICE guidance. The examples given included the case of a drug, beta-interferon, prescribed for multiple sclerosis (MS) patients, which NICE rejected on the grounds of the cost-effectiveness evidence, but the DoH subsequently advocated for funding:

E4: It's quite clear that although NICE is meant to be the central Health Authority, the Department of Health...effectively overturned a NICE decision on beta interferon...basically saying that although NICE had given guidelines that it shouldn't be used in the NHS, multiple sclerosis patients do not have options...so it was an ironic situation where NICE says, "Don't do this" and actually what you see is a huge increase in prescriptions of beta interferon because the Department of Health has got involved.

E7: NICE comes up with conclusions and they are supposedly an independent body, but then again their conclusions and recommendations may be overturned by the Department of Health, particularly when a decision is highly controversial, like beta-interferon.

E9: If you look at the MS scenario with NICE, whichever way it seemed to go, beta interferon's were not coming out as cost-effective and yet the Government, you could argue, shifted the goal posts to look at other ways of getting interferon into the prescribing setting...

These informants suggested that, for political reasons, the DoH could not support NICE's recommendation to constrain using beta-interferon. The need to avoid controversy and show that the DoH was a "caring body" (E7) overrode "rational" decision-making. In other cases, it was felt that the DoH would be inclined to use economic evaluation when it supported their political agenda:

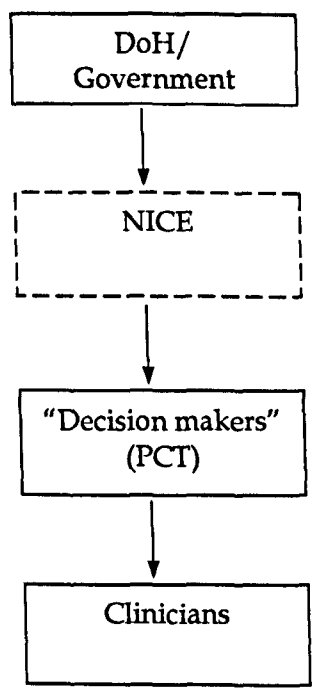
E9: ...I think they will use agencies like NICE...and they will use economic appraisals in a manner which they choose to see fit. I remember...a piece of work ...which actually got sent to the Minister of State for Health, it was to do with [equipment], and he turned round and said, "Yes, this is interesting, but what's the cheapest [equipment] now?" and he seemed to miss the bottom line message, and

there seemed to be another agenda which he was playing out and so I think they will use evidence as evidence in the argument and they will use it in order to furnish arguments to suit themselves...

The use of economic evaluation by the DoH is therefore indirect (akin perhaps to the political model of decision-making). Evidence is used if it supports a position already taken.

Despite concerns about the power of NICE in national decision-making, most economists viewed NICE a having a prominent position in the decision-making process. Thus, Figure 6.1 can be amended to include NICE as an important body in their own right in decision-making, although they can be influenced by the Government/DoH (Figure 6.2).

Figure 6.2: stylised decision-making, including NICE



3. Use of economic evaluation at the local level

In line with the focus of this thesis, informants' perceptions of the use of economic evaluation at the local level were explored. Here there were several important factors that emerged: the use of NICE guidance at the local level; the limited use of

economic evaluation locally; and alternative ways in which an economic way of thinking is perceived to be useful.

3.1 Value of NICE guidance

For the majority of informants, the main, and perhaps only, use of economic evaluation at the local level was perceived as being through NICE guidance. They felt that NICE guidance was practically mandatory, even though the guidance is officially regarded as recommendations. Hence they felt that local decision makers were obliged to follow NICE, although, in practice, one informant (E7) suggested that there was limited inspection of local decision makers' use of such guidance. This implied that, in some areas, there might be ways to avoid the guidance:

> *E7: CHI[xxi] was supposed to ask in their inspections, "Have you been using NICE guidance; if not, why not?" but there's not been much on that...*

Several informants were sceptical about the appropriateness of the NICE guidance at the local level and perceived that there was little evidence about whether the guidance had been useful for local decisions:

> *E12:...When they review the guidance, I don't think they review it in the sense of, "Well has this guidance done any good?", they review it in the sense of, "Should we change this guidance again?"*

Informants gave three reasons why implementation of NICE guidance might be problematic for local decision makers. Firstly, some informants felt that the range of topics covered by NICE was often restricted to new fields of medicine, rather than existing treatments or procedures:

> *E12: There are big issues about services that NICE hasn't looked at...there are lots of gaps, things aren't covered by NICE.*
>
> *E15:...NICE has become...very focused on new things to the exclusion of things that are being done already and I am actually becoming more interested in finding out what are things that we know are effective and cost-effective but we are not*

[xxi] Commission for Health Improvement (CHI), essentially an inspectorate at the DoH level, now replaced by the HCC (see chapter 1 for details).

doing enough of, rather than putting all our resources into evaluating every new thing that comes along, which may only affect a small number of patients and may not be contributing very much to total welfare.

For example, E15 felt that there are many diabetic patients not being adequately treated at present and that national guidance would be welcomed.

Secondly, several informants felt that implementing NICE guidance at the local level was often financially infeasible. For instance, E4 felt that:

E4:...People often say that NICE makes pronouncements without thinking of the affordability in the guidance that they're giving, which is probably a fair comment. And at the local level it's the affordability of the guidance that is important.

As a result, some informants with local experience believed that NICE recommendations were, in practice, not always implemented:

E14:....If we've got sets of guidance for £3 million and we only have half a million pounds to increase that budget...we are still saying, "No" to some things that [NICE] tells us to fund...

Although refusal to fund NICE drugs by the PCT was not the experience of this fieldwork of local decision-making, there was heated debate surrounding the difficulties in financing NICE guidance. None of the health economists with local experience discussed cases in which programmes or investments were cut back to be able to implement NICE guidance (which is similar to the experience of the local study), although it might also be a more positive financial situation. Moreover, these health economists were aware of the need to prioritise, although they felt that this might not be achieved by decision makers locally.

Finally, one informant (E4) suggested that NICE guidance was obstructing the local decision-making process. He felt that because decision makers were waiting to receive NICE guidance, they were delaying their treatment decisions:

E4: The biggest impact is what people have been calling the "NICE blight". The fact that actually people stop doing things or don't start doing things, if they know it's coming from NICE...

There was no evidence of this occurring in the fieldwork study of local decision-making, despite their being some cancer treatments undergoing the NICE process.

3.2 *Limited direct use*

In general, informants believed that there was limited direct use of published economic evaluation, other than those coming from NICE:

E5:... I am not sure if the people in...PCTs or hospitals are necessarily engaged in [economic evaluation] or see the relevance of it...

The view that economic evaluation was of limited use to local decision makers was most strongly supported by those with local experience. E6, for instance, felt that hardly any evidence from economic evaluation he had provided to the local level had ever altered decisions eventually made:

E6:...In terms of decisions altered, I think my success in the [X] years could be counted on the fingers of one hand, if not the fingers of one finger...
(From e-mail correspondence)

Furthermore, two informants (E13, E6) believed that if they resigned from their positions as heath economists, they would not be replaced. In addition, E3, who had local decision-making experience, confirmed that he had not been replaced when he resigned from his position.

However, these informants felt that the director of public health at the PCT would be the person most likely to be interested in economic evaluation (which resonates well with the findings in the previous chapter):

E13:...I would have to say the remainder of the board [apart from the director of public health] was, and remains to this day, utterly disinterested in economic evaluation, totally disinterested.

The reason for this was due to public health directors' exposure to health economics methodology during public health training:

> *E6:...The public health people I think are usually the best disposed towards health economics.*

In contrast, several informants viewed clinicians as being disinterested in economic evaluation because it was not relevant for their individual decision-making:

> *E6:...I think doctors are generally interested in the interests of the patients that are in front of them, whereas economic evaluation assumes, of course, a broad societal perspective...*
>
> *E8:...I think producing [economic evaluation] for the benefit of [clinicians] is often quite a waste of time because they are not going to change...*
>
> *E12:...I cannot imagine GPs would ever read economic evaluations, not to inform their own decisions...*

At both levels of decision-making, PCT and clinical, around a quarter of informants perceived that the only way economic evaluation would be used would be in justifying an action or position decision makers already wanted to take:

> *E14: I must say at times I am a bit nervous that [economic evaluation] is kind of a fur coat, to provide a justification for the answer they would have got anyway, rather than genuinely approaching things with an open mind.*
>
> *E6:...At a Health Authority....I presented data...and did it have any impact? I would say only when it agreed with what the pre-conceived views of the audience [were], which is not really an impact but might be about reducing uncertainty... (From e-mail correspondence)*

These informants appeared to believe that clinicians were particularly likely to use evidence "circumspectly" to justify their spending to PCTs:

> *E9: Clinicians may utilise the information if they felt that it was going to benefit them...They use information circumspectly, if they want to make a business case for example, then they will use an evaluation, which shows that particular programme in a very positive light...in trying to develop an argument for additional resources...*

E15:...[Clinicians] attitude towards [economic evaluation]...[has] got a load to do with whether they think it is going to help their argument or not and they would certainly use it if they thought that it would increase the chances of getting funding. If they thought it was going to work against them, they might discredit it or put more emphasis on other factors.

This suggests a more political use of evidence as also found in the previous chapter. These views appear to depart more radically from those in chapter 2, where evidence is assumed to be used directly to make a decision.

Almost half of the informants, from a range of backgrounds, raised issues about the measurement of use of economic evaluation. They believed that economic evaluation was often part of a wider body of evidence, so that it was difficult to measure use of economic evaluation:

E8:...We tend to produce the evidence along with other things...

E15:...A lot of the studies I have been involved in were only one part of the jigsaw.

These informants felt that it was also difficult to isolate the effect of economic evaluation on decisions that are made, because of chance factors, meaning that it might be coincidental as to whether economic evaluation is used:

E2: There was no significant way in which [the decision] differed from what we were recommending... but what I ask myself is, "Well what would have happened if we'd come up with the opposite conclusions?"...

E7: ...The problem I have with all of this is that has anyone made a decision or done something different because of what you've said or the economic evaluation that you've produced because it may just be chance, it may just be good timing, it may be a thousand other reasons that have coincided with the production of your economic evaluation and that's the really difficult thing...

This leaves the questions of, if published economic evaluation is not likely to be used, or used circumspectly, when might economics contribute to decision-making? This is discussed in the following section.

3.3 *Economics way of thinking: improvement in process and "quality" of decision-making*

Informants, tending to have local experience, felt that economics as a way of thinking among decision makers was of greater importance than the use of economic evaluation. These informants felt that an economic way of thinking could be used to improve the process and quality of decision-making:

> *E14:...Economists in Health Authorities probably need to do quite a lot of stuff that isn't economics, to kind of get through the door and then you can kind of bring out, "Well this is what you should be doing in terms of making better quality decision-making."*

E13 and E14 suggested that option appraisal or cost impact analysis was more useful than economic evaluation at the local level:

> *E14:...Your classic 'defining the problem, brain storming options, short listing them, and then kind of evaluating each of those options'...so there are probably fairly major strategic issues...*
>
> *E13:...Very much back of the envelope things, we are not down to cost-utility analysis, we're talking about almost cost impact analysis, not even more sophisticated than that.*

In addition, one-third of informants from a range of backgrounds suggested that PBMA was a useful local framework for making decisions. These informants felt that it was important for decision makers to be able to consider their total budget, what programmes money is currently being spent on, and any disinvestments (stopping or reducing programmes) which might be used to fund new investments. PBMA was raised by these informants spontaneously, feeling that this would be where economics could play the most important role in the health service:

> *E13:...I would say that probably my biggest success story ever was in using PBMA in [a particular medical field]...*
>
> *E6:...My main thrust is to get more information about outcomes so we can use programme budgeting and marginal analysis, and to try to work in more ideas of allocative efficiency.(From e-mail correspondence)*

E1:[Local decision makers] need more on the range of needs and the needs assessment; they need their total budget figures and they need to have ***tools*** *for helping them not just do the marginal decisions but also the* ***total allocations.*** *(Emphasis added)*

These informants further suggested that PBMA aided both the process and outcome of decision-making, rather than focusing solely on the outcome of decision-making (as in a cost-effectiveness ratio).

4. Barriers to using economic evaluation locally

The majority of informants appeared to be sceptical about the direct use of economic evaluation in local decision-making, feeling that, at most, it would be used to justify spending decisions to the PCT. There appeared to be three main reasons why this was the case: accessibility and relevance (knowledge of economic evaluation and economics and relevance of economic evaluation to decision-making); the health care environment (budgetary inflexibility, political barriers, and perceptive of clinicians); and incentives faced by decision makers and health economists. These are discussed in turn.

4.1 Accessibility and relevance

There were two issues raised with regard to this topic: lack of knowledge of economic evaluation among decision makers; and lack of relevant topics addressed in economic evaluation.

a) Lack of knowledge

Approximately one third of informants felt that there was a lack of understanding of economic evaluation among local decision makers. One informant (E9) felt that health economists were partly responsible for this situation, because of their tendency to use jargon and overcomplicated techniques.

E9: I wonder sometimes if health economists do overcomplicate things. It doesn't always come across in what one might call as readily available English. When you start looking at some of the health economics journal articles and see the formulas

and the diagrams and the actual subject that's being investigated, they don't exactly lend themselves either to decision-making and I wonder if we need to perhaps take on board some of those issues and try and get the health economic bottom line message across.

Furthermore, two informants (E6, E3) believed local decision makers had limited knowledge of economics:

E6:...They [the Health Authority] just didn't really know what to do with me...or the alternative would be to try and get [me] involved but mainly as a sort of a kindly accountant, "We don't want to get a Finance Officer along, you do something similar, don't you? Can't you cost it for us?" and what they were basically asking for was a budget impact thing...and you start thinking, "Do you know the difference between an economist and a finance officer?" and I don't think most of them did, they thought they were roughly the same.

E3:...My experience...was that there was no economic input other than which came from accountants and looked at what they told you what cost might be...

Similarly, some informants in the previous chapter also confused health economics with accounting.

b) Lack of relevant economic evaluation

Several informants with local experience or involvement in priority setting suggested that local decisions typically relate to reconfiguration of services and deployment of staff. These informants found that there was a lack of useful economic evaluation to address such decisions:

E14: The lack of [economic evaluations] is a bit of a problem and the type of things we evaluate and publish as economists are very rarely the types of decisions we face. So for example, presumably what you've [is the need for] a specialist lung cancer nurse, and so you go, "OK I will go and have a look for some evaluations" and there are none. The biggest decisions that we make are not around technologies, they're around individuals...The kind of crunch decisions are, "Do we have a specialist lung cancer nurse?", rather than the detailed evaluations of, "Is providing key counselling for that lung cancer nurse good to do?" So it's the type of decisions I think often have absolutely no evidence at all...

E15:...Most of the budget decisions were not about identifiable interventions, they were often about capital investment of a new ambulance station or the relocation of laundry services, modifying the pension arrangements for nurses and so on, so it was very hard to see how economics can play a strong part...

This finding is strongly supported in the previous chapter. Two informants (E1, E15) also felt that where economic evaluations existed they tended to be performed for the general setting and it was difficult to translate them to the local situation.

4.2 *Health care environment*

The majority of informants, irrespective of their background, mentioned barriers related to the health care environment. These barriers relate to budgetary silos, the political context, and (differing) perspectives among local decision makers.

a) Budgetary "silos"

More than half of the informants felt that the need for local decision makers to keep health care expenditure within their budget was a hindrance to the use of economic evaluation:

> *E4: The major problem appears to be that the decision makers are fundamentally responsible for budgets. They are not fundamentally responsible for the health gain of their population...*
>
> *E9:...People do not look outside of their own budgetary boundaries and decisions are made within those rather than looking at the implications of some of those decisions as budgetary holders.*
>
> *E6:...Managers, especially in hospital, only care about their own budgets (which might not even include the drugs budget (or alternatively might solely be confined to the drugs budget!)) and are only really interested in gross budget impact in the next year or two...*
> *(From e-mail correspondence)*

E4 added that the chief executive of the Trust in his region was effectively sacked because of an overspent budget, and no thought was given as to how the money was spent or whether it improved the health of the population.

These informants also felt that whether recommendations from economic evaluations saved money in the future was irrelevant to local decision makers

because they were not allowed to overspend in the current period and could not transfer money between budgets:

> *E2: The health economist constructs seem very unreal to decision makers. We assume that essentially you could move costs over time and provided you discount them then it doesn't matter what year they occur in, how you treat them as seen in a present value. But, those decision makers say, "Well it's not like that, we haven't got any more money this year"...*

> *E13: [The intervention]... was incredibly cost-effective, it was cost saving, it was the totally preferred option, but we could not get the Trust to agree to implement that change because it involved employing another member of staff...The bottom line is affordability and it's not even affordability over a period of time when you would look and say, "Well you would save that salary within 6 months", it's budget specific...because everyone's accountability are under their budget headings.*

E13 went on to offer an example of where budgetary silos had meant that a "rational" approach could not be used:

> *E13:...You hear things about low molecular weight heparins, great for the patients, they have less side effects, they don't have continual injections, they don't have to have their blood checked on an ongoing basis, but the benefits, the reduction in the cost of blood tests are borne by the labs and the increased costs of low molecular weight heparins over ordinary heparin is born by pharmacy, and never the twain shall meet.*

E13 felt that the main driver in local decision-making was affordability within budgets. Again, this meant that, even if an economic evaluation proved an overall cost saving, it might not be used because of a discrepancy between the groups who saved money and those who lost as a result of implementation of the study.

According to one informant (E6), there was an additional complexity: costs were fixed in the short run, which meant that tangible savings could not be made immediately from implementing an economic evaluation. In the short run, the costs of a Trust were seen as almost invariant to the number of patients seen.

> *E6: 70% of NHS costs are staff costs so if you stop some type of elective surgery and switch it to day cases, if you look at the accounting figures they'll say, "Inpatient operation costs, £1000, day case costs, £500" so you'll be like, "Brilliant, we've switched 100 patients, that's £50,000 to play with so we can invest that in a new*

community physio service or something like that." But how real are the savings? So you've stopped doing something in inpatients and switched it to day cases, so, how have you actually saved £500 per case because all the surgeons are still there, all the nurses are still there, all the pharmacists are still there, they're all fixed costs basically.

b) Political context

Almost half of the informants, from a range of backgrounds, felt that national targets and directives were a major cause of local decision makers' lack of use of economic evaluation:

> *E6:...I think there are so many targets, so many commitments made at national level, which then have to be delivered at local level...Local level now seems to me just to be about implementing what Milburn or John Reed has thought and dreamed up and made a commitment to, rather than local decision-making. So I see the local level as being more and more constrained and less and less able to respond to economic data...*

Informants suggested that because of the targets there were few local decisions to be made and hence minimal opportunities to use economic evaluation:

> *E4:...Everyone agrees that maximising health is a good thing, but that we have certain performance targets which tend to be process based rather than health outcome based...*
>
> *E5: What it's doing is distorting priorities in the sense that to deal with the access, if you define it in terms of waiting lists, it's a problem with hospitals. What we're doing is pumping more resources into hospitals, which seems to be against all the notions of primary care led health services...All that's qualitative and wishy-washy so it just gets brushed under the carpet, but actually that might be where some of the health gains are to be had.*
>
> *E6:...It seems to be quite a different world from the one I lived in 10 years ago when you could sit around and think, "What should we invest in? Shall we invest in here, or shall we invest in over there?"*

c) Perspectives

Several informants felt that the perspective of decision makers was in conflict with the perspective adopted in economic evaluation. These informants felt that clinicians tended to assume an individual or patient perspective:

E8: I do think you have got the ethical conflict between the individualistic ethic in the doctor-patient relationship and the health care ethics at the higher level, where your duty is to the population rather than to an individual.

E8: I have a lot of sympathy, even for the clinicians who often say to me, "Yeah that's very, very good what you just explained to us, but when this class is finished you're going back to your desk but I have to go and look patients in the eye and say, 'I am trading changing the way that I am treating, because of economics'" and I accept that totally...I don't have to look the patients in the eye and say, "Yes there is something available but your PCT is not going to pay for it", or "I am the guy at the PCT who made the decision at the PCT", which is worse.

Furthermore, three informants (E10, E5, E4) felt that local decision makers might feel uncomfortable with using outcome measures commonly used in economic evaluation (such as QALYs) because they relate to population averages:

E4:...QALY analysis...is very relevant to the individual. It's less clear once you add in the cost, because of course the costs aren't relevant to the individual, but they are relevant overall. So we are interested in what essentially are the differences between individual and societal decision-making.

Three informants (E12, E14, E15) suggested that factors beside efficiency, such as equity, were relevant in local decision-making and could compete with the use of economic evaluation:

E12:...There are some barriers [to using economic evaluation] which, you might say, are legitimate...they are competing objectives...like equity and health and access...

Few informants however expanded on this issue, although one (E15) suggested that economic evaluation would be disregarded if there were a lack of alternative treatments available:

E15:...There are patients who have got some problem or disease that is very difficult to treat and there is no alternative to this, so even though it might be expensive, if you don't do this you can't do anything for them...

4.3 *Lack of incentives*

The third category of barriers to using economic evaluation is the incentives or motivations for local decision makers to use the research, as well as the incentives for health economists to produce utilisable work.

a) Incentives for decision makers

There were three general factors identified which affected the incentives of decision makers to use economic evaluation. These related to the political environment, organisational change, and the negative perception among the public of using costs in decision-making.

Politics: "stick their heads in the sand"

NHS decision-making appeared to be conducted in a political environment, which made changing practice less likely:

> *E13:...I think it's incredibly difficult to effect change because you're not dealing with anything in isolation, every change that you're proposing has a political angle, it has an equity angle...if you change the benefit of one group within the NHS, the other groups are up in arms, and it's not even just medics versus nurses, it's one type if medic versus another type of medic. These types of barrier to change are huge...*

> *E6:...People who feel themselves to be under siege react in one of two ways. They can grasp hold of something like economics and hang on to it like a drowning man. Alternatively they can close ranks, arguably stick their heads in the sand, and hope it will all go away.*
> *(From e-mail correspondence)*

Informants with local experience therefore felt that decision makers faced a set of conflicting demands, which made the use of economic evaluation less likely.

Organisational change

Two informants (E9, E14) felt that organisational change hindered the use of economic evaluation because there was ambiguity as to who was responsible for decision-making and hence the use of such techniques:

E9:...I think that we are in such a changing environment in the UK that it's going to take time for these bodies to get on board with some of these techniques and what the consequences of economic evaluations are...

E15:...The whole change of structure involving PCTs makes it very hard to know who actually is making decisions and the reason why the priorities forum approach...has, for the moment, collapsed is because it's not clear if the health authorities are not making these decisions or having these discussions, who else is?

Difficulty in knowing who were making decisions implied that it was difficult to appropriately target economic evaluation.

"Bad press that anything to do with costs and economics"

Only one informant (E8) felt that decision makers might be reluctant to use economic evaluation because of the public perception that decisions are concerned with money:

E8: ...We the economists can say, "That's fine, here is the evidence – A has a huge ICER over B cannot be justified." They then translate that into policy or put pressure on our [Health Authority boards], then the press gets onto it and says, "What do you mean you're giving second best treatment and even the MPs say, "...I am sure there is something you can do in their case to see that they get the best?" ...We as the academics don't have to take the flack, but they, the politicians and the others, have to stand up in front of TV cameras and public meetings and defend what they're doing...The headlines of the newspapers is just going to be the sound bite, "You're trying to save money by refusing to pay for the best treatments." If you're the poor sod whose name and photograph is going to be there, then maybe you want to ignore the economist and go for the easy option.

b) Incentives for health economists

Two informants (E1, E13) commented that health economists produce economic evaluations largely with their own careers in mind, rather than to affect local decision-making:

E1: I think [economic evaluations are] aimed at getting something published on the whole. They're aimed at getting a career for a health economist.

E13...Most of them are written up for other economists, that's the honest answer...

Both these health economists were engaged in local decision-making and were thus aware of the limitations of published economic evaluations for the purpose of decision-making.

5. Measures to increase the use of economic evaluation

Most informants spontaneously discussed ways in which they believed the use of economic evaluation could be facilitated at the local level. There were two main measures that informants suggested: increasing the accessibility of economic evaluation; and interdisciplinary working.

5.1 Increasing the accessibility of economic evaluation

Around a third of informants, from a range of backgrounds, felt that increasing the accessibility of economic evaluation would enable greater use at the local level. Some of these informants suggested that increasing decision makers' knowledge and understanding of economic evaluation could increase accessibility. However, two informants with local experience (E6, E13) felt that decision makers needed training in the principles of health economics (incorporating concepts such as opportunity cost):

> *E6: ...One of my hypotheses is that decision makers often do not realise the implicit value judgements in their decisions. For example, "We have this drug, there's nothing else we can do." This ignores the opportunity cost which means someone somewhere is getting less health gain than they otherwise would have done... (From e-mail correspondence)*

> *E13: He [a health economist] started his talk by saying that you have to have a whole day discussion with clinicians to explain to them welfare economics, and I put my hand up and said, "That is complete rubbish, what you need to say to them is, 'If you have a limited amount of money and you want to do one thing then you can't do something else.'" And he was really taken aback by this...but I said, "I've done this, this is my job." People don't have a day to go away and learn about paradoxes and all these other things...*

As practical help, two informants (E1, E6) felt that decision makers should be provided with a testable model, containing a structure of an economic evaluation

into which local data could be incorporated, to work with under different circumstances and incorporate their own local data into the analysis.

5.2 *Interdisciplinary working*

Interdisciplinary working between health economists and decision makers was mentioned by around a quarter of informants, from a range of backgrounds, as a way of increasing the use of economic evaluation. Informants suggested that health economists should not expect their work to be used if they are not actively engaged with local decision makers:

> *E13: What would be nice would be an engagement with decision makers and I think that these need to include everyone from GPs to chief executives of organisations and I suppose my problem with the way economic evaluation goes is that there seems to be a view that you can be an academic economist sitting in a unit writing paper on health economics and somehow that influences decision makers...*

Two informants (E5, E10) felt that local champions (decision makers who are willing to promote and encourage an economic basis of decision-making within their organisation) were required to promote the use of PBMA:

> *E5: The biggest thing though is that these things need local champions who are willing to lead the process through and they need to be people who actually are within the organisation. We can do so much and have a continuous involvement as academics, with our local environment, and they are great test beds for us, but if it's never adopted by the organisations as such, then it will never take off...*

Those with local experience perceived health economists and decision makers as two polar opposites with little access to each other's worlds. They believed it was necessary to create a bridge between health economists and decision makers' worlds in order to sustain the use of economics as a way of thinking in local decision-making:

> *E6:...The more valuable contribution is to change the way people think about things...Whenever I bump into an ex-student for the first time I always ask whether they have used any of the things from the econ toolbox. Invariably the answer is the same: "No, but the way of thinking about things, in terms of opportunity costs, for example, is still very useful and something I use on a day-to-day basis." So is that*

impact? Probably not in terms of converted decisions but in terms of slow ***"colonization"*** *of the NHS it makes a bit of difference...*
(From e-mail correspondence)
(Emphasis added)

E14:...Our role is not only to do primary evaluations and analysis but is around providing that bridge: if you characterise economics as one world and the NHS as another, then actually providing that ***interpretative bridge*** *between the two is actually quite a lot of our role as well...*
(Emphasis added)

This recognises the limitations of assuming that economic evaluation can directly influence decision-making, but highlights the potential importance of economics in decision-making.

6. Conclusion

Health economists, particularly those without local experience, appeared to view decision-making at the local level according to a stylised model, where the Government is the prime decision maker making national decisions, the local level comprises the PCT making local population decisions, with clinicians making patient level decisions. This view strongly opposes that presented in chapter 4 of this thesis, where levels of decision-making were not so distinct, and where clinicians are heavily involved in making decisions at the population level. However, the findings here do support those from the local decision-making fieldwork regarding the strong emphasis on Government policy, through the targets for instance, currently in the NHS. Since neither decision makers nor health economists appear to support such initiatives, the question of who champions these targets remains.

This chapter has reiterated the potentially limited use of economic evaluation at the local level found in the previous chapter. Health economists' views about the barriers to using economic evaluation at the local level appear to reflect, to some extent, the barriers discussed in chapter 2, in terms of, for instance, lack of knowledge of economic evaluation, budgetary inflexibility, and the political context. Among health economists with local experience, however, there was

confirmation of the fieldwork conducted here regarding the types of decisions made locally, in terms of them being largely related to reconfiguration of services, which, in turn affected the applicability of typical economic evaluations. In general though, the barriers referred to by health economists interviewed here do not resonate well with those found in the previous chapter where there is more focus on the decision-making process and context.

Chapter 7: Use of economic evaluation - the decision-making perspective

Introduction

This chapter explores the main findings of this thesis in the light of other relevant research. The chapter is divided into six sections. The first section compares and contrasts views and opinions of decision makers and health economists about local health care decision-making. This section further examines findings in relation to the organisational and decision-making models described in chapter 1. The second section discusses the focus of this thesis: the use of economic evaluation; barriers to use; and incentives for greater use. These are discussed in light of the views of decision makers and health economists, and in relation to the literature presented in chapter 2. The findings have important implications for health care priority setting and the work undertaken by health economists, explored in the third section of this chapter. The fourth section evaluates the methodology and methods employed, and there are suggestions on methodology for researchers wishing to conduct any future work in this area in the fifth section. The final section of this chapter provides a brief conclusion to this thesis.

1. Local health care decision-making

Chapter 1 presented the context of local decision-making, which is important for the use of economic evaluation. This section reviews the context of local decision-making in view of the findings of the fieldwork, suggesting that there are four fundamental aspects of decision-making, which to a large extent limit the assumptions typically made by health economists. These factors have important implications for the targeting of economic evaluation.

The four aspects, discussed in turn, are:

- The role of complex network models of organisation (in comparison to the hierarchy typically assumed by health economists and the stylised model of decision-making assumed by health economists interviewed);
- The lack of societal perspective (meaning that those regarded as being responsible for priority setting may not have a societal perspective even when they are involved in population decision-making);
- The different incentives and motivations of decision makers (meaning that there is not a single decision maker and individual rationality does not amount to collective rationality);
- The breakdown of the principal-agent relationship between the PCT and the CG (so that those typically regarded as being responsible for societal decision-making are unaware of how decisions below them have been made).

Although these aspects appear to be quite diverse, they collectively suggest that the levels of decision-making are less distinct than is typically assumed by health economists and that societal decision-making, often taken for granted in health economics, may not be a major focus of decision-making. These arguments are further developed in the conclusion to this section.

1.1) Complex networks versus clear structure of decision-making

As indicated in chapter 1, there are two types of network models: wheel (hub and spokes system)[22] or all channel[22]. In the former, there are a series of networks controlled by a single unit, whereas in the latter there is no clear hierarchy and all bodies are connected to one another in the organisation. In this research, Williamson's hub and spokes model[22] is an appropriate description of formal decision-making locally and several informants also used the term "hub and spokes". There were two possible areas where the hub and spokes model would

apply. Firstly, the CG and other such groups (such as those for CHD and mental health) had a common hub, the PCT. Secondly, there was a wider network, operating between the CG, the PCT, the SHA, the cancer network, and all other clinical bodies within health care decision-making. Here the hub was the cancer network, which set the central direction for cancer services.

There also appeared to be a network organisation within the CG. Going back to Knoke and Kuklinkski's[21] definition of networks, the "persons" were those at the CG, the "object" was decision-making in cancer care, and the "events" were the decision-making of the CG:

A specific type of relation linking a defined set of persons, objects or events...called the actors or nodes. These elements possess some attribute(s) that identify them as members of the same equivalence class...
(Knoke and Kuklinkski, p.175[21])

Within the CG, there were many different individuals from various groups, all linked together through a common focus on cancer care but without any clear hierarchy, suggesting an all channel organisation.

The various forms of network organisation in health care are not typically recognised by health economists; those interviewed tended to assume that the only organisational structure was the hierarchical model. Health economists interviewed tended to view local decision-making as essentially about the delivery of national policy, implying that the organisation of health care featured the Government at the top of the hierarchy (as depicted by figures 6.1 and 6.2). It is important, however, for health economists to acknowledge the network organisation of care beneath the PCT level, since it reveals how disparate groups interact and have influence on the PCT, having implications for the targeting of economic evaluation. Thus, the PCT might not be the only appropriate body to target economic evaluations towards, since there is another level of decision-making, comprising several layers of individuals from various backgrounds who may strongly influence decision-making.

Only the new institutional economists have considered network relationships,[21, 22] although there has been a focus on transactions costs, rather than aspects of co-operation and partnership working,[25] which is not particularly helpful in understanding these organisations. The other typical models of organisation considered by health economists in the literature, (the hierarchy and market models), are not appropriate explanations of the organisation of local health care. In the literature, it has been suggested that the hierarchy model dominates the organisation of health care and there are specific identifiable periods where different models were appropriate in health care.[9] However, in this study of local decision-making, although there was an overall hierarchical structure and many decisions were based on national policy, this model is inadequate in explaining how health care is organised locally and the relationships between decision makers. Similarly, the market delivery of health care was not found to be an important organisational feature in the study of local decision makers.

These findings imply that health economists, in general, are not aware of the basic structure of the local health care organisation. It is unclear how a body such as the CG, comprising individuals from different decision-making levels, would fit into health economists' notions of decision-making.

1.2) Other objectives versus societal objectives

In the literature and in this study, "decision maker" is a term used by health economists to describe individuals perceived as having a societal role. Health economists interviewed tended to view a decision maker as being responsible for priority setting. However, the local study found that individuals taking the role of "decision maker" do not necessarily have a societal perspective and might not be focused on maximising the health of their population, as assumed by health economists. Decisions did not appear to be based on a health maximisation principle. During the fieldwork, the CG, who was largely responsible for priority setting in cancer care, did not discuss what might be best for the health of local citizens. Most decisions were not related to health outcomes but were intended to

achieve national targets and provide an accessible and equitable service. For instance:

> *S10: Everyone should have the same sort of level of care and deserve the same access to health care.*

Although this is from a societal perspective, it is not necessarily related to health maximisation.

Furthermore, other local decision-making bodies did not conform wholly to the economists' view of a societal basis. Although "the PCT" is typically viewed in the literature as a single united body responsible for societal decision-making locally, the PCT here comprised both the executive or board level functions along with groups such as the CG acting as its agents in developing policy and making decisions. The notional responsibility for decision-making was in practice diffuse so that clinicians (hospital doctors and GPs) who are usually regarded as being confined to a separate clinical decision-making level by health economists, here were part of the process of population decision-making. Those with clinical roles participating in groups such as the CG were found to have a clear impact on the decisions that were made and, of course, brought with them to this role their perspective of focusing on the individual patient or patient group. Health economists who were interviewed did not, however, see this involvement of clinicians in societal decision-making. There was an implicit understanding among health economists that clinicians were hugely powerful and that they could circumvent societal decision-making but there was less realisation that clinicians are actually part of the decision-making process. Previous work, on the use of economic evaluation in decision-making has also focused on the HA/PCT level, and where clinicians have been involved in studies, they are treated as a separate entity, in their patient-doctor decision-making, with little/no acknowledgement of their societal role.[232, 233, 247]

The local study therefore suggests that decision-making in health care cannot be viewed as comprising separate and distinct levels, with a clear role for societal decision-making. Previous studies have not been conducted using methods that would be likely to observe such findings. Although Coast[120] showed how decisions are often reinterpreted at various levels of decision-making, her work did not focus upon the extent to which the initial decision-making (both formal and informal) involves a variety of actors from the different levels of decision-making. The work of Jones[119] hints at this problem, by noting that decision makers are confused about whether to act from an individual perspective or from the perspective of their organisation but, again, the interaction between the levels of decision-making is unclear.

1.3) Different incentives and motivations of individuals versus unity of purpose

Apart from the assumptions of a clear hierarchical structure and clear societal objectives being pursued, health economists also tend to assume that there is classic rationality in decision-making (as the basis of neo-classical economics which most health economics is theoretically dependent upon). Classic rationality assumes that there is unity of purpose among decision makers. However, there is, albeit limited, evidence that decision-making at the local level might involve pluralistic bargaining, incremental decision-making, and also garbage can approaches, which conflict with classic rationality.

This local study found that the pluralistic model is applicable to decision-making at the local level, where there are different incentives facing usually rational individuals. The fieldwork has found a collection of individuals with a multitude of objectives, incorporating different levels of decision-making. Within the CG, each individual can be seen as being 'rational', having their own clear objectives and competing for a limited 'pot' of money held notionally by the PCT:

> *OA: I guess [decision-making] is about people's health?*
> *S6: No!*

OA: No?
S6: No that's very naive. It's about distribution of money.

The different motivations and incentives of CG members influenced the informal decision-making, as did the relative power of these individuals within the group. In particular, clinicians are powerful individuals in a societal decision-making body, both because of their role in treating patients and their greater level of expertise in oncology. Bargaining took place between clinicians (including GPs) and PCT members attending the group (S2, S5), with those with clinical power often seeming to be able to dictate the choices made by the CG:

S2:...There was a very veiled threat from the paediatrician that if we tried to stop the service, the public would be very cross.

Thus the individual rationalities of those involved in the process did not amount to a collective rationality, let alone to a specific objective of acting on behalf of society to maximise the health of the local population. There was no process here by which a collective rationality could be facilitated, as was recognised by one informant:

S2:... What we should be spending our valuable time...in doing is talking to each other about how to make the best of what we have got...

S2:...I'd like to say [the decisions] were all done on a rational basis that we had at the beginning done a gap analysis, that is knew where we wanted to get to, knew where we were at the time, that we had calculated the gap and then we had made rational choices between different options of getting there...

As discussion revealed (particularly at the workshop), a local strategy could not be agreed upon because decision makers found it difficult to discuss priorities from a societal perspective and were protective of their own interest groups.

1.4) Perfect agency versus breakdown of principal-agency

So far there has been a distinction between decision makers' and health economists' perceptions of local decision-making. However, this section also reveals a difference in views and opinions among PCT informants and those in the CG. This

is an important finding because it suggests that solely examining PCT/senior informants' views of decision-making is unlikely to offer an accurate description of decision-making or the use of economic evaluation.

In the local study, PCT informants assumed that local decision-making operated according to a formal process, where individual motivations and incentives are ignored and there is a focus on organisational concerns. PCT informants perceived a clear principal-agency relationship, between the PCT and the groups, such as the CG (where the PCT was the principal and groups such as the CG were the agents), with specific objectives being pursued by both principal and agent. Although there was acknowledgement of a two-way process between these groups and the PCT, it was assumed that this worked well. In particular, PCT informants felt that group members should be, and were, advising the PCT about where to allocate resources. In this respect, they believed it was the group's role to act as their agent and inform them about where they should be investing and disinvesting based on a strategy. However, the fieldwork suggested that it was not at all clear that the CG at least was acting in this way, as they did not have a clear plan of what they should and should not invest in. Furthermore, some informants were adamant that priority setting was not part of their role:

SS8: ...It's not my job, it's not what I am employed to do...

As suggested in the previous section, it appeared that it was difficult for some CG informants to take a population perspective, even when sitting on a body that was meant to take a societal view. Indeed, this even applied to the chair of the CG, who was sometimes influenced by the emotional pleas of CG members. The PCT tended to view the CG decision-making process as being rational, and informed by evidence, although this was not how the CG were operating in practice. Whilst PCT informants were aware of the organisational difficulties in decision-making, shaped by their position in the organisation, they were not aware specifically of the problems faced by groups such as the CG. Their lack of understanding of the

informal process revealed that they were not entirely sure how the decisions that reached them had been made in practice.

Although there were some references to agency relationships among the health economists interviewed, these agency relationships were largely perceived as being between the local (PCT) level and the national or SHA level. The notion of agency between those lower down in the decision-making process and the PCT was not recognised by health economists, as it was largely assumed that the PCT is the main decision-making body. There is an implicit assumption among health economists interviewed that the PCT are making societal decisions, with little recognition of the information feeding into their decision-making. Furthermore, although the literature has discussed principal-agency in health care, the focus has been on whether this achieves efficiency, and the appropriate role for the Government.[17] Principal-agency at a local level has only been covered in depth by one study,[226] finding that there was a weak link between the principal-agent chain of commissioning, which often led to non-compliance with decisions.

Another area of principal-agency relationship that appears to be important from the fieldwork, but has not been covered in any great detail in the health economics literature, is trust. It is often assumed that the principal cannot trust their agents, and thus must devise contracts to ensure their co-operation, but as this study revealed, there was also mistrust by agents of their principal. In the local study, some clinicians (hospital doctors and GPs) felt that the PCT might be taking a proportion of the budget even before it is allocated in order to cover their deficit. Although previous studies on the use of economic evaluation have recognised the low-trust relationships that are common in the NHS,[48] they have not reflected upon the implications for decision-making in any great depth, as here where lack of trust is likely to lead to a breakdown in principal-agency relationships (where agents do not trust that their principal is acting fairly and the principal does not trust the arguments being put forward for funding proposals, meaning that neither feel that they are basing their decisions on 'perfect information'). Other studies have also sought to examine trust largely in relation to contracts in service provision.[66] The

notion of trust was not mentioned by any of the PCT informants interviewed, because they assumed that partnership working was being achieved. Likewise, health economists interviewed did not refer to issues of trust and it is missing from neo-classical economic theory, which is unsurprising given that social relationships are largely ignored.

Summary

The study of local decision-making found that pluralism is of importance in understanding local decision-making. Individuals were guided by their own rationality, but this did not amount to rationality being pursued by the CG as agents of the PCT. The garbage can model of decision-making has been applied at the local level[119] but there was little evidence to support this here since, individually, decision makers appeared to behave rationally. Furthermore, the garbage can model ignores individuals' attempts to make the process more rational as was certainly desired by some informants. Incrementalism can be applied to some aspects of decision-making by the CG, in terms of them making decisions based on what had been agreed to be funded previously, but, again, this model does not reflect most of the decision-making that took place locally. Pluralism seems to best represent the nature of decision-making, with decisions being the product of bargaining between individuals pursuing their own rational ends.

Although classic rationality is of limited relevance since there was not one decision maker operating in a clear decision-making environment with an obvious decision to make, adaptations to rationality, notably game rationality, are important for understanding some aspects of decision-making in health care at the local level. For instance, as to why a priority for breast cancer treatment was included in the funding list to the PCT, the chair of the CG replied:

> *SS2:...Because the lead clinician is the person who runs the breast clinic and she would be very upset if we didn't have it in...*

The chair knew that the priority would not be accepted by the PCT (since he was not really planning to advance it further), but including it in the list was a means of

pacifying the clinician and maintaining the social relationships that were vital to the working of the group.

To summarise these findings: at the local level, the network model of decision-making, without a clear hierarchy, was present. There were different actors, with clinicians having a role as part of the population/societal decision-making. This study implies that the levels of decision-making cannot be so clearly characterised, as is typically understood by health economists, who assume distinct levels of decision-making, more in line with formal decision-making, but not even recognising a two-way process. In some respects, PCT informant's views may be similar to health economists, in assuming classic rationality. This study has further shown how the PCT is not necessarily aware of how decisions that reach them have been made. These findings suggest that health economists' view of the organisation of local decision-making is too simplistic and that, to enhance understanding they need to develop broader models of decision-making. In particular, conducting studies that focus only on the PCT level, without exploring groups feeding into this level, are likely to offer limited understanding of decision-making in practice.

Thus, the organisational structure and process of decision-making is of great importance to understanding the behaviour of individual decision makers, which inevitably affects their use of economic evaluation. These have largely been ignored in the literature on use of economic evaluation. The next section focuses on the findings in this fieldwork on the use of economic evaluation, where, again, contrasts are made between the views and opinions of health economists and decision makers, particularly those situated within the CG.

2. Use of economic evaluation

The local study found no instances where decision makers used economic evaluation to inform or make decisions. Although option appraisal was performed for some services by the Trust, these were by no means economic evaluation and

did not incorporate benefit measures common to health economists, as also found by McDonald.[48] The majority of informants, however, did understand basic concepts of economics, such as scarcity, opportunity cost, and efficiency, although they were not applied in any systematic way and they did not appear to be always at the forefront of decision makers' minds (since the concepts tended to come to light only when probing questions were asked following the workshop). Efficiency was an important criterion according to some informants in making improvements in the future to the way that services are delivered. However, this term, as with the term "cost effective", was used in a rather colloquial way to mean something "good", rather than in the way typically understood by health economists. These findings imply that *economics* is only ever likely to be used indirectly, as in the enlightenment model of research utilisation,[148] whereby knowledge penetrates into individuals' ways of thinking over time. Findings, therefore, that economics is mostly likely to be used indirectly contrasts with health economist's assumptions of economic evaluation being used directly to make a decision.[298] Interestingly, the assumption that *economic evaluation* will be used directly was not the opinion in general of health economists interviewed, who believed that such evidence might be used by decision makers as political ammunition to support decisions they wanted to make. Since economic evaluation was not used in the fieldwork, it was not possible to test this assumption, although some decision makers suggested that they would use research evidence to support their funding proposals.

There are three explanations for the limited role of economic evaluation in decision-making. These factors, discussed below, were not considered before the research began. In addition, PCT informants were unaware of these barriers to using economic evaluation, feeling that groups feeding into them, such as the CG, were using such evidence already.

2.1) Lack of clear societal decision-making

Health economists tend to assume that there is a clear decision-making setting, with identifiable decision makers, all interested in maximising the health of their

local population. As the previous section suggested however, this was not the case. Decision makers did not necessarily have a societal role and often had differing incentives, which meant that a clear objective was not being pursued, even within a societal decision-making group such as the CG. As a result it is difficult to know how economic evaluation could be used:

> *S2: This is possibly why rational techniques, like health economic approaches, don't take hold. There isn't enough stability in the system to allow custom and practice to include deeply rational approaches like health economics.*

Here, the garbage can analogy may be more appropriate. In the garbage can model[75], problems, solutions, participants, and choice opportunities are thrown together, and it would be purely by chance whether economic evaluation entered into the decision-making process or not. Considering the fieldwork however, it seems that neither problems (largely managerial), solutions, participants (each with their own objectives) or choice opportunities (the nature of decisions relating mostly to the employment of staff) supported the use of economic evaluation.

Although a wide range of barriers at the organisational and decision-making level have been suggested in the literature on use of economic evaluation, it has not previously been found that the lack of a societal perspective means that economic evaluation would not be used directly. The literature on the use of economic evaluation suggests that those in clinical roles may not take a population perspective[4], but it is assumed that other groups do have this perspective.[4] In addition, health economists interviewed tended to assume that the PCT is the local societal decision maker, without being aware of other 'societal' groups.

2.2) No relevant studies

Findings from the local study revealed that the topics typically addressed in economic evaluation did not concern the type of decisions being made. Most decisions were about the reconfiguration of services:

S1:...We are talking about the need for more nurses, the need for specialist nurses, and things like chemotherapy, the need for new pieces of kit...

In contrast, economic evaluation tends to evaluate specific treatments. As a result, it was apparent that the applicability of economic evaluation was limited, as observed during the CG meetings and mentioned by one informant:

S2: [Economic evaluations] are not available and it is difficult to translate crude questions...

S2: If I can say this, studies do not apply...

This was also recognised by health economists with local experience who were interviewed, although academic health economists did not mention this as a barrier and felt that most decisions in the NHS concerned treatments. Although lack of relevant economic evaluation has previously been identified as a barrier in the literature on the use of economic evaluation, it was difficult to interpret what this meant since some studies suggested that data were not generalisable,[230, 235, 243] rather than they were irrelevant. This is likely to be the case since most studies did not explore the decision-making context and in some studies, barriers to the use of economic evaluation were presented on a list, with little scope for decision makers to offer their own opinions. The study by McDonald[48] did, however, suggest that there is a difference in the type of work undertaken by health economists and decision makers:

Problems do not present in neat packages for economists to tackle and...the mainstream HA business was carried on elsewhere, outside the orbit of the health economist.
(McDonald, p.95[48])

2.3) *No incentives to produce utilisable work*

Some health economists suggested that there were few incentives to produce utilisable research. The literature on the use of economic evaluation has ignored the incentives facing health economists, viewing them as an external and exogenous factor. In the study of health economists however, there was some indication that health economists' primary concern is to produce research that

benefits their career, rather than work aiding decision makers. Part of the explanation for this might be the lack of incentives for health economists to be involved in decision-making (health economists with experience at the local level suggested that they were demoralised because their work had little effect on decision-making). However, it is also likely that health economists view publication of economic evaluations as a positive step in their career and wanting to produce work in order to enhance a career has been found to exist for researchers in general.[149, 162, 167]

2.4) *Facilitating use of economic evaluation*

Health economists and decision makers interviewed had very different views about how to increase use of economic evaluation. As suggested in the literature, there is a common view among health economists that:

> *Economic evaluation...should more often be used, and ways can be found to increase its use...*
> (Drummond, p.9[174])

This might explain why health economists interviewed have focused on *incentives* to increase use of economic evaluation, through methodological developments and improvements in techniques of economic evaluation.[2, 3, 168] Health economists interviewed also suggested that overcomplicated techniques and jargon were used in economic evaluation and that to remedy this would facilitate greater use:

> *E9: I wonder sometimes if health economists do overcomplicate things. It doesn't always come across in what one might call as readily available English, when you start looking at some of the health economics journal articles and see the formulas and the diagrams...*

It is assumed that once economic evaluations are improved, this will facilitate their use. However, the study of local decision-making suggests that such initiatives would not enhance the use of economic evaluation, since this was not a barrier to their use. In areas where economic evaluation is already being used, it might well be important to concentrate on improving the quality of studies.

Some health economists interviewed suggested that there ought to be interdisciplinary working with decision makers at the local level. However, there was little indication as to how this might be achieved. Health economists interviewed might be aware that their research is not going to be used if not actively disseminated, but they did not propose any way in which this could occur, except through 'interaction', which was a rather vague term.

More likely in contexts such as the one observed for this thesis, it would be useful to concentrate on attempts to make decision makers' implicit priority setting more explicit. The majority of CG informants were not aware of their implicit priority setting and what they were "really" doing. Although they felt they were prioritising already, they were unaware of the value judgements in their decision-making and some felt that their priorities must be funded irrespective of anything else. This lack of awareness of implicit priority setting among decision makers was also recognised by a health economist with local experience:

> *E6: ...One of my hypotheses is that decision makers often do not realise the implicit value judgements in their decisions. For example, "We have this drug, there's nothing else we can do." This ignores the opportunity cost which means someone somewhere is getting less health gain than they otherwise would have done... (From e-mail correspondence)*

These findings suggest that it would be useful for health economists to present and explain the implicit behaviour of decision makers, and to "translate" it within explicit economic evaluation approaches. This would help decision makers to understand where economic evaluation could be used, and possibly escape from pre-conceptions of economic evaluation by some decision makers, as found in the local study:

> *S1: [Economic evaluation] is not something I am terribly interested in to be honest, this is public health type of study, it's comparative, you have to look at the quality of the research, and that is potentially very time consuming, unless you know quite a lot about it, which I don't. It's not something I am personally interested in so I keep well clear of it to be honest...*

If it had been possible to extend the research reported here, one option would have been to hold several more workshops which could have offered practical ways of prioritising, based on the notions of scarcity and opportunity cost, possibly within a PBMA framework. Health economists could aid the comparative scoring of priorities, which was felt to be difficult to achieve by decision makers.

> *S2: It is difficult to make decisions between programmes...*
>
> *S1:...[Scoring priorities based on certain factors] is very difficult to do because it is very difficult to comparatively score and get it right...*

PBMA attempts to find out how decisions are made and what the relevant information is. PBMA has assumed a more interactive model of research utilisation, focusing on the collaborations between decision makers and health economists. As Weiss points out, it is likely to be more rewarding to start from exploration of the decision-making process (as done in PBMA) than to start from a desired outcome from this process (which is the focus of economic evaluation):

> *Social scientists who talk about research use always seem to start at the research end. They ask: How can we induce people in decision-making positions to pay attention to our work? A more fruitful entry into the discussion seems to me at the policy end: How do policies get made? What information do decision-making groups seek to pay attention to?*
> (Weiss, p.10[149])

An opinion leader would be required to follow the process through since it is worth noting that the workshop was only facilitated because of the insistence of the chair of the CG. This is further supported by some health economists' experience at the local level in which they felt that without some key members of the board of the PCT being on their side, they would have been restricted in their ability to influence decision-making.

Summary

In summary, the barriers found in the study of local decision-making are in part associated with the decision-making context, where there are few societal decisions to be made and the type of decisions are related to reconfiguration of services, rather than treatments. These barriers are not typically recognised as being of great importance either in the literature or amongst academic health economists interviewed in this study. These findings suggest that there needs to be greater awareness of the local decision-making context among health economists if the use of economic evaluation is to be understood further. In addition, to counter the lack of societal decision-making, decision makers ought to be made aware of where societal decision-making could be used within the CG. Overall, PBMA is a useful tool for decision makers, possibly dealing with the problem of relevance of economic evaluations and the importance of local data as highlighted by some informants interviewed.

Finally, there are also barriers to the production of useful economic evaluations on the researcher's side, as acknowledged by some health economists interviewed in this study. This point has not been recognised in the literature on the use of economic evaluation, highlighting the value of the research presented in this thesis.

3. Implications of the findings

The study of decision makers and health economists has important implications for improving the local priority setting process and the work undertaken by health economists. Implications for local priority setting presented here are largely related to the CG where most of the recommendations that the PCT received were developed.

3.1) Implications for local priority setting

Williamson[27] claimed that networks are likely to eventually fail because of management and co-ordination problems. However, within the local study, health care decision-making could be, and was only ever perhaps, negotiated through

some form of networking. Most decision-making is informal, comprising many different individuals and groups, often linked together, but without any clear hierarchical structure. Since the creation of the NHS, there has been an active role for a wide range of decision makers, including clinicians and managers. Understanding the organisation of care in terms of hierarchy or (quasi) market is therefore likely to offer little explanation for the way in which decision-making occurs at the local level. In this sense, there is no reason why Williamson would be correct in assuming that networks fail in time. There was evidence, for instance, that partnership working, facilitating trust and potential commitment among decision makers, had enhanced during the sixteen months observation of the CG. This suggests that it would be useful for local decision-making groups in other geographical areas to be organised in a similar way where no such processes already exist. These groups would require strong leadership from the chair, which was felt to be fundamental to the success of the CG by some informants interviewed in this study. For instance, as S8 pointed out:

> *S8:...[The chair of the CG] has worked really well on our behalf and I am sure that comes as a result of having a good relationship with him.*

In addition, it would be helpful to improve upon the shortcomings of the CG, since many decision makers felt that they needed help when making decisions and there was no scoring of priorities, which hindered a clear approach to priority setting. This suggests a potential for other people being members of such groups, other than decision makers, such as health economists.

It would appear that approaches for priority setting based on economics (scarcity, opportunity cost, and the margin) which are also attuned to the process of decision-making will be helpful at the local level. Several decision maker informants (such as S1 and S2 in particular) said that they wanted to be able to score or rank priorities, but they were unsure how to proceed in this respect. They felt that it would be useful to weight different criteria, but S1 acknowledged that this would be a complex task as many of the programmes typically considered are very

different from each other (for instance, comparing the employment of extra oncology staff versus buying a new piece of expensive equipment). Although decision makers did not mention the use of economics as an explicit way in which to prioritise, it was evident that economics could help decision makers to compare the costs and benefits of different programmes that they are considering and to consider potential disinvestments that could be realised to fund new investments. Use of concepts such as opportunity cost could create awareness among decision makers of explicit tradeoffs (*e.g.* cutting back on one service to fund a new service). However, if economics is used as a way of prioritising, there must be some realisation of the budget available for cancer services (which was not known to any of the decision makers), so as to assess which investments are feasible and the magnitude of cutbacks that are needed.

One approach based on economics is PBMA, as recommended by some health economists in the UK, although it has had mixed success.[112] PBMA, as discussed in chapter 2 of this thesis, is an economics approach to prioritising (resting on the notions of opportunity cost and the margin), but it also emphasises the importance of the decision-making process (since in various PBMA studies, stakeholders meet to discuss the factors that are important to them when making decisions and the relative weights that they should receive, in order to rank priorities). Such ideas resonate well with the findings at the local level, where the CG comprised the main cancer decision-making forum and already involves various stakeholders. The literature on PBMA suggests that the approach is most likely to be sustained if it is supported by opinion leaders[112] and there is trust among decision makers;[112] both of which were found to be important factors influencing decisions in the CG. PBMA could be facilitated through workshops such as the one conducted in this study, allowing greater familiarity among decision makers about ways in which to prioritise using economic principles. Such workshops, by being 'hands-on', could also permit familiarity with research evidence such as economic evaluation.

3.2) *Implications for work of health economists*

Health economists' focus upon maximisation of QALYs may not help in ensuring utilisation of economic evaluation at the local level. Decision makers' objectives are multi-faceted and they are motivated by different organisational, financial, and personal concerns. Furthermore, QALYs are rarely applicable to the local level since benefit measures are broader - they are not necessarily related to health but to other benefit measures - than those typically considered in economic evaluation. This might account for two health economists' experience of local decision-making:

> *E6:...We're drifting away from things like maximising cost per QALYs within a given budget...but that's one of the lessons from the health service...*

> *E3:...It's not economic evaluation of a technology, unless you define technology very widely to include the process by which funds are allocated to units within the health service. You could just about squeeze it in if you want, but it would be a very broad definition. I spent a lot of my doing that, I saw that as economics, but it doesn't fit the kind of standard definition of economic evaluation...It's not doing a cost per QALY, it's not cost effectiveness analysis...*

E6 felt that there was the potential to drift away from maximising cost per QALYs because, at the local level, there were a variety of objectives of local decision makers being pursued at any one moment in time, such as equity and politics.

Thus, there needs to be an appreciation among health economists that cost per QALY might not be an objective being pursued at the local level. Although maximisation of QALYs has been strongly questioned in the literature[193, 340, 341, 276, 342] for many health economists it is still seen as an appropriate objective.[193, 278, 343] Instead of being directly used in decision-making, economic evaluation could contribute to a general culture of information about cost effectiveness. Health economists need to understand this process of decision-making in order to be more aware of how the principles of economics can be useful to local health care decision makers.

Furthermore, health economists could usefully widen their understanding of human behaviour by focusing not just on neo-classical theory, but on epidemiology and psychology, as well as being more aware of health policy, in order to understand different ideas about human behaviour not related to classic rationality. This could potentially be achieved by encouraging employment of health economists in medical departments, rather than (health) economics departments, as has also been suggested by Phelps and Maynard,[344, 345] as well as training during degree studies in health policy and disciplines related to other research methodologies. These initiatives, however, need to be sustained in the long run, and it would be useful for funding bodies to request work where economists engage with decision makers. Within academia, Research Assessment Exercises (RAE's) may produce perverse incentives to focus on methodological quality rather than the likely impact of work on decision-making. Certainly health economists require incentives to produce utilisable research since they are, essentially, like decision makers, looking for work:

> *An organisation is a collection of choices looking for problems, issues and feelings looking for decision situations in which they might be aired, solutions looking for issues to which they might be the answer, and decision makers looking for work.*
> (Cohen, March and Olsen, p.2[75])

These findings do not suggest a wholehearted abandonment of economic evaluation, but an awareness of its limitations and a focus on the wider context of decision-making. Where economic evaluation might be particularly useful is through cost-consequence analysis, which does not assume maximisation of QALYs and contrasts different options in tabular form for all the relevant costs and benefits, allowing decision makers to impute their own values, thus alleviating the potential problem of relevancy of economic evaluation, but still providing an explicit approach. Cost-consequence analysis could also inform PBMA.

Thus, in the UK at least, the clearest role for economic evaluations using CEA or CUA is through the NICE process. Here, it might be of interest to health economists to focus on producing good quality guidance, since the local level

responds to such guidance. The NICE process of decision-making is arguably more 'rational', since NICE defines a clear research question and commissions research on the topic,[269] suggesting fewer of the complexities of local decision-making. However, it is important to bear in mind the resource implications of NICE initiatives. NICE guidance should allow flexibility, since some health areas will be unable to afford implementing the guidance and the opportunity cost of implementation will be high, in terms of forgone community developments. Further, opportunity costs vary across local areas – a factor which is not included in NICE assessments:

> *S1:...The Government can't measure [quality of care] because they are not clinicians...So it is for us to make the judgement, because, at the end of the day, if you cannot administer a NICE drug safely, then you shouldn't be using it...*

Here, S1 felt that if appropriately trained nurses were not available to administer particular NICE drugs, it was harmful for patients to receive the treatment.

Summary

The literature on the use of economic evaluation has assumed that the responsibility for improving the use of studies in practice largely rests with decision makers, once the methodology has been improved and the principles of economics communicated. However, findings in this thesis suggest that decision makers are largely organised in a way that is conducive to priority setting, but need to make their decision-making more explicit in order to score priorities for instance. This implies the need for health economists to be aware of the local decision-making process, and potentially to become much more involved in this process. Findings further suggest that this would mean being less focused on producing typical economic evaluations, which, here, were not found to be particularly useful to local decision makers.

4. Reflection on methodology and methods used

This thesis has aimed to explore the views and opinions of local decision makers and health economists about the use of economic evaluation in decision-making.

The studies of both groups used (a modified approach to) grounded theory,[315] located within a constructivist/interpretative paradigm,[302] using qualitative methods. The ontological, epistemological, and methodological stance was therefore different to that typically used by (health) economists. However, the perspective taken in this research enabled the views and opinions of informants to emerge and allowed the development of theory over time. Although in depth qualitative research has previously been performed in studies exploring the use of economic evaluation,[48, 252] this study has arguably gone further than this, attempting to gauge opinions not only about evidence, but also awareness of concepts and economic modes of thinking, which has only been possible through the paradigm and perspective associated with qualitative research. In contrast, previous literature has tended to focus on the direct use of economic evaluation.[4]

An important aspect of the research of local decision-making was the use of methods triangulation. The model was based upon the direct observation of actions, documentary evidence and accounts of individual informants. This further enabled insight into how decision makers say they behave and how they behave in practice. During interviews, it was possible to cover subjects in depth, and the use of interviews and observations in combination allowed a greater depth and breadth of subjects to be covered. The use of methods triangulation was particularly important during the time of the workshop, in which it was possible to both directly observe the workshop and to gain individuals' views and opinions about the event. The use of observations allowed topics to arise in their own natural setting, which may not have arisen in interviews. In addition, the observations allowed rapport to be developed between informants and the researcher, thus creating a more favourable environment during interview. Furthermore, the iterative nature of the research allowed reflection on the design of the study and, for instance, facilitated a response to the needs of the chair of the CG in terms of the workshop.

Of particular importance throughout the study was the fact that local decision makers, apart from the chair of the CG, were not aware of any focus on

economics.[xxii] This meant that they had fewer incentives to exaggerate its impact or importance. Unlike previous empirical studies in this area, where it has been obvious that health economists are performing the study or that the focus of the study is economic evaluation, there was no incentive for informants to misconstrue their use of economic evaluation. This might explain why, in this study, no use of economic evaluation was found, whereas previous studies have suggested a 30% use (although the specific meaning of 30% use, when trying to address how economic evaluation is used and in what ways, is questionable).

It has not been possible to extend the research of local decision-making with respect to four areas. Firstly, if possible, it would have been desirable to observe other programme areas apart from cancer. However, attempts to access other programme groups within the time available were unsuccessful. On the other hand, the focus of the interviews conducted with decision makers was not cancer programmes in particular and it was possible to interview informants from the PCT outside the CG. Secondly, the time for the study fieldwork was limited to sixteen months. Within the funding constraints it was not possible to extend beyond this period, although it would have been ideal to have a longer period to follow-up after the workshop, to determine whether it made any difference to decision-making in the long term. Given the limited impact even in the short term, however, this is unlikely to be the case. Thirdly, the views of other stakeholders in decision-making, including citizens, patients, and carers were not solicited in this study, as this was not the focus of the project. Finally, it would have been desirable to extend the study to a different location, to another PCT. However, given that the research was in-depth and the focus was to observe and reflect on decision-making using a variety of different methods, it would not have been possible to cover more than one area in the same depth. In addition, a number of economists who worked in other health service areas identified similar issues to those found in the study of local decision-making.[256]

[xxii] A situation did not arise during the fieldwork where it was necessary to reveal to the group my background as a health economist.

In the study with health economists, only semi-structured interviews were used. Semi-structured interviews did, however, allow important topics to be covered within a short time frame. Participant observation would have been impractical for examining health economists' views and opinions of decision-making. Focus groups may have allowed topics that the researcher was not aware of to emerge through discussion, although, as the researcher is a health economist, this is less of a problem than it would have been with an unfamiliar group. Focus groups alone would have been unlikely to provide sufficient depth. Additionally, for obtaining informants' views and opinions about what could be a sensitive subject, it might have not been successful. In addition, informants might have held back information related to their potential colleagues (such as, for instance, E1's comment that the vast majority of economic evaluations are produced for the benefit of other health economists).

The collection of data from health economists was iterative and data that emerged helped to refine the topics contained in the interview schedule. Possible limitations of this aspect of the study were the use of telephone interviews, rather than face-to-face interviews, which meant that potential nuances were lost and it was sometimes difficult to establish a strong level of rapport with the informant. However, in view of the resource constraints, it was not feasible to conduct face-to-face interviews, given the wide geographical spread of informants.

Although generalisability is not usually thought of as an aim of qualitative research, some researchers, such as Hammersley[331] suggest considering the typicality of cases in relation to the general population or whether the model developed is likely to resonate to other particular contexts. Considering the study of decision makers, there are three ways in which this might not be the case.

Firstly, the selection of individuals participating in the research might not have covered all possible roles within the health service. However, those identified by informants as important to the decision-making role were all interviewed. Potentially a larger study could go beyond the level of decision-making studied

here, to include those at a 'higher' level (for example, the SHA) and at a lower level (for example, pharmacists and allied health professionals).

Secondly, the fieldwork for this thesis was conducted at a time during which there had been substantial change for the NHS as it moved to PCTs. In terms of typicality of cases, organisational change and uncertainty are likely to have affected all geographical areas, although different areas might have had different levels of such uncertainty. However, subsequent changes to the organisation of health care, in terms of method of delivery, may make this research less generalisable, although there have been no recent major changes.

Finally, the locality studied may be different to those in other localities such that the pressures on local decision-making are different or non-existent. However, there is no reason to believe that these pressures would be different in other areas given that many of the problems identified relate to national issues (in relation to the targets) or organisational issues that are likely to be present in other areas. Indeed, the vast majority of health economists interviewed suggested that national directives (such as the targets in particular) created a huge obstacle for local decision-making. Further, the findings of the fieldwork resonate strongly with the comments made by health economists working at the local level [for example, regarding the type of decisions being mainly around staff and organisation, rather than technologies (E13, page 231, E14, E15, page 243), or around the main interest in economic evaluation coming from the director of public health (E6, E13, page 238-9). On the other hand, the fieldwork area faced severe financial difficulties and informants gave the impression of "scrambling to fit within the resources". This situation would have been likely to affect the specific context of decision-making observed and the particularly severe financial pressures faced by local decision makers. In addition, the lack of financial resources cannot account for the weak priority setting mechanisms in place: on the contrary, it might be perceived to be more likely that decision makers would want to prioritise care, knowing they could not possibly hope for all their wish list items to be funded. It was therefore an interesting context within which to examine the research topic.

Furthermore, the fieldwork area chosen for this study was specific in that it had pre-established programme groups delivering care in accordance with various NSFs or the national plans (such as the cancer plan). As a result, unique programme areas were identifiable, together with the decision makers feeding into these groups. Decision makers implied that local care health care delivery in other geographical areas would have worked in a similar way to these programme groups, although they felt they would be more or less advanced depending on the organisational skill of the PCT. Moreover, the literature on health care decision-making has identified unique programme areas for delivering care, for instance for stroke[125] and coronary heart disease.[48] It is likely that the fieldwork area is typical in many ways of the organisation of local health care decision-making in England.

During the study with health economists, a wide variety of opinions were sought, ranging from health economists with local experience (or priority setting experience) to those with only academic careers. Informants were sought from England, Scotland, and Wales, in an attempt to gain insight into different organisations and patterns of care. In this respect, the study with health economists was based on a wider geographical area than the study of decision makers. However, it is questionable whether the body of health economists represented in this thesis is representative of health economists working in the UK. Those in this study tended to be relatively senior, with relatively large amounts of experience of economic evaluation, and some had worked at the local level as health economists. Given this, it is likely that this study of health economists overestimates the level of understanding of health care decision-making and/or the role of economic evaluation in decision-making compared to the understanding of health economists more widely. In addition, this study did not attempt to assess the views and opinions of health economists working in consultancies or pharmaceutical companies, although these individuals might have had substantially different viewpoints.

5. Further research into this area

Research in other localities should try to assess how generalisable these findings are. If replicated elsewhere, health economists would benefit from moving away from questioning the use of economic evaluation, to understanding more about the decision-making process, and more about how economics can be of practical use in decision-making.

In further exploration of the decision-making context and process it is likely that quantitative techniques would be largely unhelpful and qualitative methodology and methods should be adopted instead. Only one study, by McDonald,[48] exists which is comparable to this research in terms of objectives and methods used. McDonald was an active member of the decision-making group, being part of the process of decision-making and a decision maker. She was known to be a health economist, advocated the use of economic techniques and provided economic analyses to the group:

At this meeting I presented a paper version of a computer model which, I suggested, the group could use to examine the costs and benefits of various strategies for the diagnosis and management of suspected heart failure...although the group members passed around a hard copy running to about ten pages illustrating model parameters and data-input fields, there was agreement that this approach was perhaps a little too sophisticated for the group...
(McDonald, p.139-140[48])

McDonald's strategy therefore provides a very different perspective from the research reported here. Respondents in another qualitative study in this field were also aware that the focus of the research was on the use of economic evaluation.[252]

However, possible future work would benefit from being conducted across different locations and across a broader context with settings involving the SHA, to a greater degree, and other groups not included in this study, such as pharmacists and allied health professionals. In the international context, further qualitative work is required, since all of this work has taken place within a UK setting. It is

likely that differing cultures and organisational systems would require re-examination of the findings in this study.

Finally, other research might involve qualitative assessments of the value of introducing PBMA. Controlled experiments of different interventions might be conducted, for instance to find out the outcome when using PBMA in one area compared to decision-making without PBMA in another area.

6. Conclusion

The problems associated with the use of economic evaluation in decision-making are not so much the constraints which health economists are aware of but a lack of understanding of the decision-making process and therefore the inability to target economic evaluation in the right direction. Understanding rationality is useful for understanding the behaviour of decision makers, since they can be seen as being rational, but just not in the way that economists perceive rationality. Perhaps more importantly, individual rationality does not equate to organisational rationality, with a specific objective of acting on behalf of society. This is not usually recognised by health economists. The local study found that there were many different groups and individuals in decision-making, so that the clinical 'level' was often merged with population decision-making. This is also something not typically recognised by health economists. This thesis has therefore provided insight into how priority setting decisions are made (or more often not made, or are avoided) at the local level in the NHS.

This study found no role for usual economic evaluations, although there is potentially a clear role for priority setting approaches based on economics (with PBMA being the main example in the literature). Another important contribution of this thesis to health services research is that it is has provided further and unique evidence of the growing concern that 'technical' health economics approaches to priority setting do not fit well with the culture and management processes of the NHS. The PBMA approach was recognised as being useful by health economists, suggesting its feasibility in theory (although further evidence might be required to

assess its feasibility in practice). PBMA offers a way of reconciling the decision-making context with a more objective criterion based on fundamental notions of scarcity and opportunity cost. More so, however, economists can potentially be extremely useful to decision makers by enhancing the use of economics principles in decision-making, so that this enters into an interactive model of research utilisation. Being useful in this respect is likely to create a change of mood of health economists who are pessimistic about their work being used, as suggested in chapter 2. Thus:

> *Because people expect research use to occur through the sequence of stages posited by [the problem-solving model], they become discouraged when events do not take their expected course.*
> (Weiss, p.427[148])

Appendix

Extract 1: Information sheet

INFORMATION SHEET

NHS decision-making

Researchers at Bristol University are carrying out research to understand local decision-making in the NHS. We want to find out who makes decisions, how they are made and what information is used. We are doing this by observing meetings where health service funds are allocated between different alternatives. We would also like to talk separately with you about how you feel about these meetings, and about local decision-making in general. This would take about an hour and if you agree we would like to tape-record the discussion.

It is up to you to decide whether you take part in the study. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without a reason.

If you have any questions about the study, please contact me, Oya Asim (E-mail Oya.Asim@bristol.ac.uk or call 0117 928 7352).

Extract 2: Consent for observation of meetings

CONSENT FORM FOR OBSERVATION OF MEETINGS

Title of Project: NHS decision-making

Name of researcher: Oya Asim

Please Tick

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I have no objections to [CG] meetings being observed by Oya Asim. ☐
3. I therefore agree to take part in this study. ☐

Name of Attendee:.....

Position:.....

Date:.....

Signature:.....

Name of Observer:.....

Date:.....

Signature:.....

Extract 3: Workshop presentation slides

Decision Making for Cancer Services Workshop: An Economist's Approach

Jackie Brown
MRC Health Services Research Collaboration
Department of Social Medicine
University of Bristol

Workshop Outline

- Basic economic concepts: opportunity cost, efficiency, incremental approach
- Types of economic evaluation
  - Decision rules
- Programme budgeting and marginal analysis
- Application to cancer LDP

Economics

- What is economics?
  - Concerned with the consequence of ***choices*** made within existing resources

Basic Concept: Opportunity Cost

- Scarce resources ⌫Choices ⌫Sacrifice
- By using resources in one particular way implies forgoing the benefits obtain in using the resources in some other way

Basic Concept: Opportunity Cost

- Opportunity cost
  - Value of the resources in terms of the forgone benefit which could be obtained in their next-best use

Basic Concept: Opportunity Cost

- Opportunity cost in a treatment area such as oncology

  E.g. by investing resources in extending the age of breast screening you may have to forgo new drug treatment in oncology

Basic Concept: Efficiency

How do we decide how we are going to allocate our limited resources?

Choices should be made so as to derive the maximum total benefit from finite resources

Efficiency is *not cost cutting!*

Basic Concept: Technical Efficiency

- Are we producing output in the best way possible, without wasting resources?
  - Minimising input to produce a given output
  - Maximising output with given inputs
- Treatment area eg breast screening – 1 vs 2 view, double vs single reading, frequency of screening, age group screened

Types of Questions

- Alternative clinical strategies eg medical management vs. surgery
- Place of care eg outpatient vs. GP
- Timing of interventions
- Whether to screen vs. health promotion

Basic Concept: Allocative Efficiency

- Are we producing the mixture of care to maximise outcomes/benefits?
  - Sector or health service eg cancer strategy
  - Health service
  - Society as a whole

Economic Evaluations

- Comparison of two or more alternative
  - ***costs*** –resource use consequences and
  - ***benefits*** (outcomes, effects)– non-resource consequences
- Incremental approach

Types of Economic Evaluation

Cost minimisation	Clinical and/or patient based
Cost effectiveness analysis	Natural units
Cost utility analysis	QALYs
Cost benefit analysis	Monetary units

Decision rules

An efficient option:

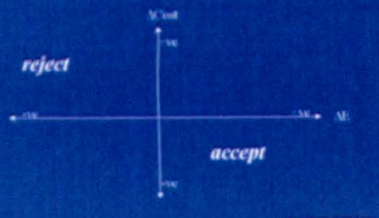
- Costs less and is at least as effective
- Costs the same and is more effective

Example

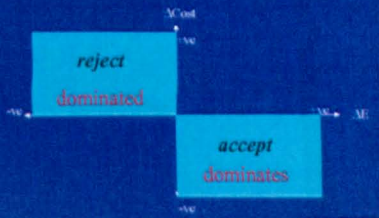
Treatment for locally advanced or metastatic breast cancer

Treatment	Cost	QALYs
Capecitabine	£ 1268	0.73
Vinorelbine	£ 1513	0.55

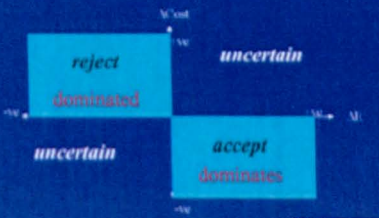
Cost-effectiveness plane



Cost-effectiveness plane



Cost-effectiveness plane



Incremental cost-effectiveness ratio

$$ICER = \frac{C_A - C_B}{E_A - E_B}$$

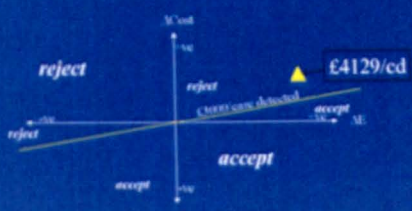
ICER = additional cost per additional unit of effect

Breast cancer screening

- 2 view screening vs. 1 view
- ICER : Cost per additional cancer detected with 2 views = £4129

Cost-effectiveness plane

Cost-effectiveness plane



Lymphocytic leukaemia treatment

Oral fludarabine vs CHOP:

ICER = £1,220 per QALY gained

Cost-effectiveness plane

Decision rules

The efficient option:

- Costs less and is at least as effective ***(dominant)***
- Costs the same and is more effective ***(dominant)***
- Cost more and is more effective and the additional effect is considered worth the additional cost

Treatment/procedure	Cost/Q.A.L.Y (£ Aug 1990)
Cholesterol testing and diet therapy only (aged 40-69)	220
Neurosurgical intervention for head injury	240
GP advice to stop smoking	220
Pacemaker implantation	1310
Valve replacement for aortic stenosis	1140
Hip replacement	1310
Cholesterol testing and treatment	1490
Kidney transplant	4710
Breast cancer screening	5590
Heart transplant	7640
Home haemodialysis	17 260
Hospital haemodialysis	21 970
Erythropoietin treatment for anaemia in dialysis patients (assuming a 10% reduction in mortality)	54 390
Neurosurgical intervention for malignant intracranial tumours	107 760
Erythropoietin treatment for anaemia in dialysis patients (assuming no increase in survival)	126 290

MRC HSRC

Programme Budgeting Marginal Analysis (PBMA)

Helps decision makers maximise the impact of health care resources on the health needs of the local population

- **Programme budgeting**
  - an appraisal of the past and current expenditure in specified programmes eg. cancer strategy, care of the elderly, diabetes

MRC HSRC

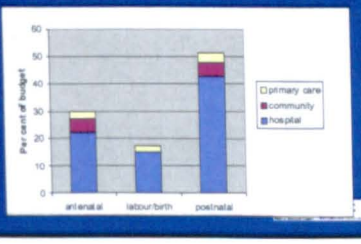
Programme Budgeting

- Expenditure estimated by considering:
  - Inpatient days
  - Outpatient visits
  - Primary care

MRC HSRC

Programme budgeting: example

Grampian maternity sub-programme budgets 1976/7
Source: Gray and Steele 1979



Programme Budgeting

- Used to highlight options within and between programmes
- Doesn't appraise or evaluate but helps focus on where to apply techniques of evaluation

MRC HSRC

Marginal Analysis

Incremental approach :

- The appraisal of the added benefits and added costs associated with a proposed investment
- The appraisal of the lost benefits and lower costs associated with a proposed disinvestment

MRC HSRC

PBMA

1. Choose a meaningful set of programmes eg within the cancer strategy
2. Identify current activity and expenditure in those programmes (total budget + ?)
3. Think of improvements/investments –wish list eg LDP

PBMA

4. Consider the incremental costs and incremental benefits
5. Think of disinvestments
6. Consider the decrease in costs and decrease in benefits
7. Prioritise as a list according to cost-effectiveness and other decision making criteria
8. Consult widely
9. Decide on changes
10. Effect changes

Conclusion

- Difficult choices need to be made in terms of what can be afforded
- Current usage of economic evaluation mainly at national Level
- Decisions still need to be made at local level
- Efficient decisions need to consider the incremental costs, incremental effects and opportunity cost

Extract 4: Exercise for workshop

Exercise for discussion

Look at the Cancer Local Development Plan, 2004-2010:

Programmes	Develop/ Not yet Programmed	Investment programmed/ Implement

Look at the adapted Cancer Local Development Plan for programmes <u>not yet developed</u> and try and prioritise the programmes:

Programmes	Incremental Cost	Incremental Benefit

CONTENTS DELETED FOR CONFIDENTIALITY REASONS

You should consider the following:

- Your budget constraint

- An estimate/guesstimate of the incremental cost and incremental benefit/outcome

- What the opportunity cost of each programme might be

Discuss any problems with this approach

Extract 5: Evaluation form for workshop

Evaluation of Priorities Workshop

1) Have you attended this kind of workshop before?

Yes ☐ No ☐

2) Do you think what you have learnt today will help you in future decision-making?

Yes ☐ No ☐

Why?

_____

_____

_____

3) Would you like more help of this kind in the future?

Yes ☐ No ☐

4) If so, what would you like covered by future workshops?

_____

_____

_____

_____

5) If this workshop is run again what suggestions do you have for improving the presentation?

_____

_____

_____

_____

6) Did you find the workshop useful?

Yes ☐ No ☐

Extract 6: Pre-workshop invitation to interview

Title of e-mail: Health Care Decision-Making

Dear X,

I am undertaking research on health care decision-making in the local area for my PhD. I am aiming to find out how decisions are made in the area and who is involved in the decision-making process. As you will be aware, I have been observing the [CG meetings].

I would be extremely grateful if you could spare the time to talk with me about your personal views and opinions of the decision-making process. I would also like to tape-record the conversation if possible. I would like to assure you that our conversation will be strictly confidential and anonymity will be guaranteed.

If you are available to meet, please could you tell me the dates and times you are free?

If you have any questions about the research you can contact me by e-mail (Oya.Asim@bristol.ac.uk) or by telephone on 0117 928 7352.

I look forward to hearing from you and hope you would like to be involved in this research.

Kind Regards,

Oya Asim

Enc.

Extract 7: Post-workshop invitation to interview

Title of E-mail: Use of Economic Evaluation in Priority Setting

Dear X,

Following from the research I am conducting on local decision-making for my PhD at the University of Bristol, I would like to ask whether you would be willing to speak with me about the use of economic evaluation in priority setting, by you and the group. This is a theme of my project that I am particularly interested in pursuing, as a result of the workshop "Decision-making for Cancer Services Workshop: An Economist's Approach", held in January 2004. Even if you think that you are not the best person to discuss this topic, or you did not attend the workshop, I am still very interested in whatever you have to say. The interview will be completely confidential and anonymous. The interview will be face-to-face and will take approximately one hour of your time. If you agree to being interviewed could you please tell me:

-The possible dates you would be free for approximately one hour from March onwards?
-Whether you would agree for the interview to be tape-recorded?

I will contact you in a few days to find this out, or alternatively in the meantime please do not hesitate to contact me by e-mail (Oya.Asim@bristol.ac.uk) or by telephone (0117 928 7352).

Many thanks,

Oya Asim

Extract 8: Information sheet for interview

INFORMATION SHEET

NHS decision-making

I am a PhD student at Bristol University carrying out research to understand local decision-making in the NHS. I am undertaking interviews to find out who makes decisions, how they are made and what information is used. An interview would take about an hour and if you agree I would like to tape-record the discussion.

It is up to you to decide whether you take part in the study. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without a reason.

If you have any questions about the study, please contact me, Oya Asim (E-mail Oya.Asim@bristol.ac.uk or call 0117 928 7352).

Extract 9: Consent for interview

CONSENT FORM FOR INTERVIEW

Title of Project: NHS decision-making

Name of researcher: Oya Asim

Please Tick

1. I confirm that I have read and understand the information sheet dated ..... (version.....) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐
3. I agree to take part in the study. ☐
4. I agree to be interviewed. ☐
5. I agree to be tape-recorded ☐

Name of Interviewee:.....

Date:.....

Signature:.....

Researcher:.....

Date:.....

Signature:.....

Extract 10: Pre-workshop interview schedule

1	Interviewees name	
2	Position/title	
3	How long in the position	
4	Date	Day [ ] Month [ ] Year [ ]
5	Time	[ ] until [ ]
6	Location of interview	

- What does your role involve/how does priority setting work in your area?
- Which types of decisions are made concerning cancer in your area?
- Who makes these decisions?
- Where are they made?
- How are they made? In a meeting?
- What type of factors are important in priority setting?
- Which types of decision-making bodies exist in your area that you are aware of?
- How do you make interactions with these groups?
- Do you think the way decisions are made is the right way?
- Is there an appeal process?
- How could it be improved?
- Do you use any 'formal' evidence?
- Is there anything you would like to ask?

Extract 11: Post-workshop interview guide

1	Interviewees name	
2	Position/title	
3	How long in the position	
4	Date	Day [ ] Month [ ] Year [ ]
5	Time	[ ] until [ ]
6	Location of interview	

THE WORKSHOP

If did not go:

- Was it because you were unable to or were not interested?

If did go:

- Did you find the presentation useful?

- Do you think what you learnt at the workshop will help you in future priority setting?

- Had you attended that kind of workshop before?

- Would other types of workshops (not involving economics) have been more useful?

USE OF ECONOMIC EVALUATION BY YOU

- Do you think that the priority setting/decision-making process has changed since our last interview?

  (Prompt: Decision makers, communication; relationship between primary and secondary care; organisational change/uncertainty; financial situation)

- What do you mean by economic evaluation?/what terms do you associate with economics in health care?

- Do you have any experience of using economic evaluation in the past?

  If so, have you used general economic concepts, or specific studies - if latter what topic(s) were they on?
  Where do you obtain (it) them?
  If not, why not?

- Do you think it is part of your role to interpret and appraise evidence relating to economic evaluation?

  Why?
  Why not?

- What factors do YOU think are important in priority setting?

USE OF ECONOMIC EVALUATION BY GROUP

- Does the group use economic evaluation?

  Why?
  Why not?
  Do they understand economics?

- What factors do think are important TO THE GROUP in priority setting?

  (Prompt: Equity, need, quality of care, risk, effectiveness, politics, cost, organisational needs)

- How important are these factors TO THE GROUP in priority setting relative to economic evaluation and why?

- Should economic evaluation be used more?

  Why? Why not
  Why isn't it used more?

Extract 12: Invitation to interview with health economists

Title of e-mail: Use of Economic Evaluation in Health Care Decision-Making

Dear X,

I am undertaking research into the use of economic evaluation in health care decision-making. I presented a proposal for this work at the HESG meeting in January 2003. One suggestion from this meeting was to compare economist views of decision-making with those of NHS decision-makers.

I have taken up this suggestion and I am therefore conducting telephone interviews with leading health economists who have some input into economic evaluations. The telephone interviews will last approximately half an hour and they will mainly concern the interviewee's perceived use of economic evaluation, the target audience, and who the decision makers are thought to be.

I would be extremely grateful if you could spare the time to talk with me. I would also like to tape-record the conversation if possible. I would like to assure you that our conversation will be strictly confidential and anonymity will be guaranteed. I have attached a consent form for you to sign and return to me by post on the address below, if you agree to take part. I would be grateful if you could specify possible dates for the interview.

If you have any questions about the research you can contact me by e-mail (Oya.Asim@bristol.ac.uk) or by telephone on 0117 928 7352.

I look forward to hearing from you and hope you would like to be involved in this research.

Kind Regards,

Oya Asim

Enc.

Extract 13: Consent form for interview with health economists

Title of Project: Use of Economic Evaluation in Health Care Decision-Making

Name of researcher: Oya Asim

	Please Tick
3. I confirm that I am willing to take part in a telephone interview with Oya Asim on an agreed date for approximately half an hour.	☐
4. I agree to the interview being tape-recorded.	☐
5. I thereby agree to take part in the study.	☐

Name of Interviewee:.....

Date:.....

Signature:.....

Researcher:.....

Date:.....

Signature:.....

Possible dates and times for interview:.....

.....

Upon completion, please send by post to the following address:

Oya Asim
Department of Social Medicine
University of Bristol
Canynge Hall
Whiteladies Road
Bristol BS8 2PR

Extract 14: Interview schedule for health economists

- How many economic evaluations have you performed?
- Have they been intended to inform local policy, drug companies, national policy *etc*?
- Have you performed or been involved in performing any economic evaluations for NICE?
- If so, what and how many economic evaluations?

[Decision-making]

- Who do you think are responsible for decision-making?
- How does local decision-making work?
- Have you been involved in local decision-making?

[Now focusing on one or more evaluation in their own experience that, in their perception, had a big impact]

- What did this evaluation(s) concern?
- What type of information did it impart?
- Do the evaluations produce any *advice* for making system wide decisions?
- Who are the results from economic evaluations aimed at?
- Who do you think are the users of health economics information?
- Do you know whether those making policy decisions take up the findings in practice?
- How do you think they are used?
- Do you think that economic evaluations are used widely in practice?

  Why?
  Why not?
  By whom?

- What do you think are the barriers to using economic evaluations?

Extract 15: Pre-workshop coding sheet

Decision-making
Formal Process
Different levels and layers
The decision makers
Decisions made
Timescale
Informal Process
The decision makers
Power
Autonomy
Lack of explicitness of process
Reluctance to make rationing decisions
Non-decision making
Relationships
Asymmetry of Information
Mistrust of primary care
Mistrust of secondary care
Context of decision-making
Change/uncertainty
Causes of change/uncertainty
Organisational uncertainty
Personnel uncertainty
Financial uncertainty
Cultural change
Consequences of change/uncertainty
Difficulty in planning
Financial
The cause of financial difficulty
The effects of financial difficulty
National Policy
Philosophy/ideology
Specific policies
NICE
Impact of Guidance
Cancer Plan Targets
Impact of targets
Decisions made
Conflict- local and nat. priorities
Effect of missing targets
Efforts to meet targets
NSFs
Guidelines

Health Economics
Use of HE terminology
Use of HE rationale
Efficiency, scarcity, opportunity cost
NICE
Other factors
Equity
Need
Quality of care
Risk
Use of CE
Use of EBM
How use HE
Access to HEs
Barriers to using HE
Acceptability
Culture
Local level
Clinicians
National level
NICE
Expense
Quality of Care
Timing
Emotive
History
Accessibility
Incentives
PCT commissioners
Political
Financial
GPs
Political
Financial
Secondary care
Patients
Financial
Government

Extract 16: Post-workshop coding sheet

Factors in priority setting decisions
Equity (GPs)
Risk (clinicians)
Cost (not usually clinicians, usually GPs)
Political choices
Non-economic approach to priority setting
Emotive/value judgements
Needs assessment
Historical allocations
Core services
Economic "approach" to priority setting
Directly
-NICE (clinician)
-Cost effective prescribing (GPs)
- Published economic evaluations
Indirectly
-Way of thinking
Barriers to the Economic "approach"
Contextual/cultural factors
-Politics/targets
-Emotive/press/public pressure
-Non-decision-making
-Uncertainty (no idea how much money available)
-Reluctance to make rationing decisions
- Reluctance to make disinvestments
- Topics of economic evaluation

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